The development, validity, reliability and practicality of a new measure of palliative care: the Support Team Assessment Schedule.

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ABSTRACT

Hospices and support teams offering palliative care have increased by over four fold in the U.K. during the last decade. However, evaluations have been limited, often because of a lack of suitable outcome measures. This study aimed to develop and test the validity and reliability of a measure of palliative care provided by support teams.

Through detailed discussion of work objectives with care staff, assisted by review of the literature, the Support Team Assessment Schedule (STAS) was developed. STAS has 17 items, each scaled 0 (best) to 4 (worst), with definitions for each scale point. Median time to complete a STAS rating was 2 minutes (range <1 - 15). Face validity was demonstrated by use in five settings.

Criterion validity was assessed by comparing team ratings with ratings from patients and family members (or other carers) collected through interview. Patient and team ratings showed moderate correlations (rho ranging 0.45 - 0.66 for 5 out of 7 items): team ratings were usually closer to those of patients than those of family members. As a test of construct validity, quality of life (HCRA-QL) index items were shown to correlate with similar STAS items in patients more than four weeks before death (a STAS sub-scale of six items was correlated with the total HRCA-QL, Spearman rho = -0.45).

Reliability of STAS was assessed by comparing the ratings of different staff. Out of a total of 45 patient assessments, 16

items showed agreement or ratings within one score in 88% or more cases, Cohen's Kappas were greater than 0.48 (up to 0.87) and were highly significant ($p < 0.0005$). There were high correlation coefficients (Spearman's rho ranged 0.65 - 0.94).

Split-half reliability and internal consistency was assessed using Spearman Brown coefficients and Cronbach's alpha for ratings at referral, at death or discharge, and on all weeks (combined). The coefficients ranged 0.68 - 0.89: slightly higher than the coefficients found for the HRCA-QL index.

Serial scores of patients that improved (the majority) and deteriorated (a minority) under care, and results from first and last assessments of patients under the care of five support teams, indicate that the STAS was discriminating in practice. Although STAS was used to audit support team care the items are relevant to the assessment and evaluation of palliative care in other settings.

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1. INTRODUCTION

This thesis describes the development, validity, reliability and practicality of a new measure of palliative care, the Support Team Assessment Schedule (STAS).

Palliative services have expanded rapidly during the last 20 years, to assist in the provision of holistic care and relief of symptoms for dying patients and their families. This expansion has brought new challenges for accountability, evaluation and research (Dush and Cassileth 1985). In a climate of increased cost effectiveness within the health services, hospice growth will not be supported by health authorities unless the care is evaluated. Hillier (1988) pointed out that for the new speciality to speak with authority those working in palliative care "must continue to plan services, strive for long term funding and be willing to submit themselves to audit and peer review".

Although a wide variety of measures have been developed to assess health status and quality of life or to aid clinical practice, none adequately assesses the outcomes of palliative care. These measures tend to concentrate on functioning or daily living, or on single aspects such as pain. They have not included the wider aims of palliative care and have rarely included any assessment of the family's experience. When measures were adapted for palliative care they were usually insensitive to changes close to death.

Evaluations have been hampered by the lack of measures and failings in research design. These have assessed various outcomes believed to be associated with good palliative care, including pain and symptom control, daily living or quality of life (using established scales), patient and family anxiety, depression and satisfaction, place of care and cost to the health service (e.g. Parkes 1979a and 1980, Cartwright and Seale 1990, Kane *et al* 1985, Mor *el al* 1988c, McCusker and Stoddard 1987). No study has found palliative care to be worse than conventional care in these respects. In some cases little difference has been found (Parkes 1985, Morris *et al* 1988), but more commonly palliative care has been associated with increased satisfaction and better symptom control, and home care with greater periods in the terminal period spent at home (Parkes 1979b and 1980, Hinton 1979, Hannan and O'Donnell 1984). However, only two randomised controlled trials have been carried out on hospice services, both in the USA. One showed little difference between in-patient hospice and conventional care (Kane *et al* 1984 and 1985,) the other demonstrated benefits for home care (Zimmer *et al* 1984). In both conventional and hospice settings the care of dying patients is suggested to have improved over the years. This has been attributed largely to the educational effect of the hospice movement (Parkes 1985).

The cost of care has been studied in many units. In-patient hospice care varies from unit to unit , but is usually cheaper to the health service than conventional care (Hill and Oliver 1984 and 1988, Kidder 1988b). Home care is considerably cheaper, at

between one quarter and one third the cost to the health service (see Parkes 1980, Kidder 1988a and 1988b).

The evaluations to date show that palliative care is a viable alternative to conventional care. Future evaluations will need to demonstrate the effectiveness of care, and in particular to identify where care is most effective. Clinical audit is one method of achieving this, although before this can proceed better measures are needed.

This project aimed to develop valid, reliable and practical outcome measures of palliative care. The measures are aimed primarily for use in support team and community settings, and for use in the audit of care, although their adaptation for other settings is discussed. The work required a number of stages. First, the items and ratings for the Support Team Assessment Schedule (STAS) were developed and then tested for face, content and consensus validity and initial practicality. Then criterion and construct validity, reliability and internal consistency of STAS were tested. Finally, STAS was tested for practicality in the audit of five support teams in the south east of England, and the results analysed to determine the effectiveness of care.

The discussion considers the methodological difficulties encountered during the work, possible ways these may have been overcome, the properties of STAS compared with other measures, and the potential future developments and uses of STAS. A summary of conclusions is given.

2. AIMS

2.1 Aim

To develop outcome measures of palliative care which were valid, reliable, practical and useful to audit palliative care in support team and community setting.

2.2 Objectives

The aim included the following objectives:

1. To develop items suitable as outcome measures for palliative care which reflected the work and goals of palliative teams.
2. To develop methods of scaling the items in the measure.
3. To test the face, content and consensus validity of the measure.
4. To test the practicality of the measure for an audit of care.
5. To test the criterion and construct validity of the measure.
6. To test the internal consistency and inter-rater reliability of the measure.
7. To determine if the measure could be used to assess the effectiveness of palliative care in different support teams, and provide useful information on when and where care was not effective.

3. LITERATURE

3.1 Palliative care

3.1.1 Development of palliative services

Over the last 20 years there has been an increasing interest in the care of dying patients, especially cancer patients. In the U.K. and Ireland the number of in-patient specialist units or hospices grew rapidly from 17 in 1969 to 145 (with 2,600 beds) in 1990 (Lunt and Hillier 1981, Hospice Information Service 1990). The number of support teams, offering palliative care at home or through advice in hospitals, in the U.K. has grown exponentially in the last 21 years, from the first team in 1969 (Parkes 1980) to 317 teams in 1990 (Hospice Information Service 1990). In 1988 palliative medicine became a medical speciality (Hillier 1988).

A similar growth has occurred in the United States of America (USA) which has over 1,500 hospice programmes and in Canada which has over 200 (Mor and Masterson-Allen 1987, National Hospice Organisation 1985). In Australia there has been a rapidly expanding growth in interest and services over the last six years (Cavenagh and Gunz 1988). In November 1988, the Hospice Information Service (1988) knew of 30 hospice programmes in Australia. Lichter (1990) describes 23 in New Zealand. In other European countries services are expanding more slowly: Germany is known to have five in-patient hospices and three support teams, and France one in-patient hospice and 12 services offering support at home (Hospice Information Service 1988). However, many new services are planned (see, for example, Albrecht 1990).

3.1.2 Why was palliative care developed?

There were several reasons for this growth. A variety of studies showed that dying patients suffered severe, unrelieved symptoms, particularly pain, had unmet practical, social and emotional needs, and suffered as a result of poor communication, both between health professionals and from them (Wilkes 1965 and 1984, Cartwright *et al* 1973). Their families also had suffered poor communication from health professionals, and needed emotional, practical and bereavement support (Parkes 1978, Bowling and Cartwright 1982, Cartwright *et al* 1973). Cancer patients were found to have high psychiatric morbidity, while their families often developed social and psychiatric problems (Maguire 1980). Attention shifted to home care when further work emphasised the increased severity of many problems while the patient was at home, where the main burden of care fell (Ward 1974). Also, care at home could be provided more cheaply and may be preferred by many patients (Working Group on Terminal Care 1980, Creek 1982). The voluntary sector was largely responsible for initiating many of these studies and outlining standards of good practice (Lunt and Hillier 1981, Saunders 1978). Taylor (1983) argues that the voluntary nature of early hospices gave them the opportunity to develop their own models of care and to establish standards of excellence.

3.1.3 The palliative model of care

Palliative care is concerned with the study and management of patients, and relief of their suffering, when cure is impossible. The focus of care is the quality of remaining life (Doyle 1987).

Many clinicians describe these patients as terminally ill. Hospices and support teams specialise in providing palliative care, although many patients on general wards in hospitals also require palliative care.

Although in Britain the term hospice usually refers to a unit with in-patient beds, in the USA the terminology differs. There, hospice refers to the philosophy of care, and hospices programmes include in-patient units and home care support teams. This thesis will use the British definition, and will attempt to clarify whether the American units provide in-patient or home care.

Hospices

Hospices offer symptomatic, spiritual, social and emotional support and treatment to people suffering from a terminal illness, usually a cancer. Support following bereavement is also offered. The unit of care is the patient and his/her family and friends. The hospice model is of holistic care in a homely atmosphere (Saunders 1978, Parkes 1979a, Taylor 1983). Most patients admitted to hospices are no longer responding to curative treatment, but there are exceptions (McCusker 1983). Patients may be admitted for care until death, for respite care, or for control of symptoms (Saunders 1978, Parkes 1979a, McCusker 1983). The average length of stay is short (St Joseph's Hospice 1988, reported a mean stay of 21 days).

Hospices are often independent buildings, sometimes on a hospital site but more usually in a separate unit, such as a converted house or home. Occasionally, a ward or dedicated beds within an NHS hospital block are deemed a 'hospice' (Hospice Information Service 1990). Most hospices (112 out of 145, 77%) are funded wholly or mainly by voluntary contributions, including contributions from cancer charities, e.g. the Cancer Relief Macmillan Fund, Marie Curie Cancer Care, (calculated from listings in Hospice Information Service 1990). In 1989, the Department of Health gave eight million pounds to voluntary hospices and support teams in England and Wales: this money was distributed by Regional Health Authorities (Department of Health 1989a). In 1991 the figure rose to seventeen million pounds (Department of Health 1991). The Scottish Home and Health Office already provided funding to voluntary hospices.

Support Teams

Support teams are based either in hospices (32%), hospitals (13%) or in community units (55%) and usually work within the National Health Service (calculated from listings in Hospice Information Service 1990). They visit and advise on any patients admitted to hospital, although the teams rarely have admission beds for their own use. They accept referrals from hospital specialists and general practitioners but will visit patients at home only if the general practitioners agree. In the community, the general practitioner and community nurses are expected to remain involved in the patient's care and offer 24 hour on-call care; however, teams provide extra support for these community services, both

with advice and shared care, some teams also providing a 24 hour on-call service (Parkes 1980, Ward 1985, Lunt and Yardley 1986).

3.2 Measures of health care and palliative care

3.2.1 Structure, process and outcome: the underlying model for the measurement of health care

The model of structure, process and outcome has been used over the last 40 years to measure health care. It is adapted from manufacturing industry: raw materials (structure or input) are handled in a certain manner (process) to produce a finished article (outcome) (Shaw 1980).

Sheps outlined the earliest model (Donabedian 1980). He classified hospital quality assessment into four categories, the pre-requisites, elements of performance, clinical evaluations, and effects of care (Sheps 1955). Donabedian (1966) built on this theme, and outlined three approaches to assess quality - structure, process and outcome. His categories were similar to Sheps, but combined the two middle components of the Sheps model into process (Table 3.1). Recently, variations on this triad have been suggested, although these incorporate Donabedian's basic framework (Table 3.1).

Table 3.1 Alternative formulations of approaches to quality assessment and their interrelationships. Source, Donabedian 1980.

Investigator	Elements of the Formulation			
1. Sheps 1955	Prerequisites, desiderata	Elements of performance	Clinical evaluations	Effects of care
2. Donabedian 1966	Structure	Process		Outcome
3. De Geyndt 1970	Structure	Content	Process	Outcome, Impact
		Content	Configuration	End result, Impact
4. Donabedian (modified) 1970	Structure	Process		Outcome
5. Dror 1968	Input, Structure	Process	Nominal output	Real output

3.2.2 Structure, process and outcome: in health care

In health care, structure represents the relatively stable characteristics of the providers of care, of the tools and resources they have at their disposal, and the physical and organisational settings in which they work (Donabedian 1980). Structure includes the human, physical, and financial resources needed to provide health care.

Process represents the activities that go on with and between the practitioners and patients. In simpler terms, Shaw (1980) described it as the *use* of resources. It includes measures of throughput and whether patients were assessed and treated according to agreed quality guidelines (Donabedian 1980), such as treatment protocols. Guidelines are based on the values or ethics of the health profession or society (Donabedian 1980).

Outcome represents the change in a patient's current and future health status that can be attributed to antecedent health care. If a broad definition of health is used, such as the World Health Organisation (WHO) (1947) definition of total physical, mental and social well-being, then improvements in social and psychological functioning are included. Donabedian (1980) included patient attitudes (including satisfaction), heath-related knowledge and health related behaviour within the definition of outcome.

The structural characteristics of care influence the process of care so that its quality can be either diminished or enhanced.

Similarly, changes in the process of care, including variations in its quality, will influence the effect of care on health status and outcomes. Thus, there is a functional relationship as follows:

structure --> process --> outcome.

3.2.3 Measures of structure, process and outcome: their use and meaning

Structure is easiest to measure because its elements are the most stable and identifiable. However, it is an indirect measure of the quality of care and its value depends on the nature of its influence on care (Donabedian 1980). Structure is relevant to quality in that it increases or decreases the probability of a good performance. Although structure is important in designing health services, to measure the quality of care it can only indicate general tendencies.

Process is one step closer to changes in the health status of individuals. The advantage of process is that it measures the most immediately discernible attributes of care activities. However, it is only valuable as a measure once the elements of process are known to have a clear relationship with the desired changes in health status (Donabedian 1980).

Outcome reflects the true change in health status, and thus is the most relevant for patients and society. However, Donabedian (1980) argued that changes in health status are useful as a

measure of quality of care only if other causes for change have been eliminated. For example, prior care or other factors may be equally important. A useful approach is to focus on the difference between the desired outcome and the actual outcome (Shaw 1980). Services can then identify whether or not their goals are being achieved and investigate any failings.

3.2.4 Choosing measures relevant to the goals of care

It is important to ensure that measures are relevant to the goals of care, as this influences validity (De Geyndt 1970). For example, it is not appropriate to use mortality rates to assess care which aims to reduce pain, discomfort and anxiety (Donabedian and Arbor 1982). Also, when monitoring the effects of an intervention, instruments should be able to measure those aspects of health and disability that are susceptible to change within the time span of the study (Bowling 1988). MacKenzie *et al* (1986) demonstrated that, although the Sickness Impact Profile described the functional status of different groups, it was unable to detect improvements in patients.

Relevant outcome measures are much more difficult to develop than process measures, especially if these are to include the total definition of health. Over the last 40 years it has becomes increasingly important to develop relevant outcomes for health care. Mortality rates have reduced during this century and, as a consequence, health care has aimed increasingly to improve health status and quality of life (Katz 1987). The development of

palliative care is a move even further in this direction - to improve quality of life while a person is dying, and to improve the quality of death.

The following sections will review measures of health status and quality of life and their value in palliative care.

3.2.5 Health status and clinical measures

Florence Nightingale was one of the first to use outcome measures other than mortality: she used three categories, 'relieved, unrelieved or dead' (Rosser 1985). Since then, a wide range of clinical and health status measures have been developed. These include quick scoring systems to aid clinical practice or decision making (e.g. the Apgar score, Apgar *et al* 1958, or the Trauma Score, Boyd *et al* 1987); measures designed for epidemiological research (e.g. the Nottingham Health Profile, Hunt *et al* 1984); and measures for clinical research (e.g. measures of quality of life for use in cancer trials, Ganz *et al* 1990, Hollandsworth 1988).

3.2.6 Positive versus negative health

Measures of health status usually take health as a baseline and then measure deviations away from this (Bowling 1991). In effect they measure ill health. It is easier to measure variations from health than to measure health itself (Bowling 1991). Early measures concentrated on the absence of disease, and then later on symptoms, mobility, the ability to carry out everyday tasks. Later still, the concept of social health was

developed. Donald *et al* (1978) described this as follows:

> 'Measurement of social health focuses on the individual and is defined in terms of interpersonal interactions (e.g. visits with friends) social participation (e.g. membership in clubs). Both objective and subjective constructs (e.g. number of friends and a rating of how well one is getting along respectively) are included in this definition'.

Broad measures of health status include the Sickness Impact Profile (Bergner *et al* 1976) and the Nottingham Health Profile (Hunt *et al* 1984). Although neither measures positive functioning both include components which measure the impact of illness on the person's life and well-being. Separate measures have been developed to measure psychological status, for example the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983) and the General Health Questionnaire (Goldberg and Hillier 1979). The measures of health status, quality of life and psychological status have been reviewed in detail by Bowling (1991), Maguire and Selby (1989), Selby and Robertson (1987), Teeling Smith (1988), and Fowlie and Berkeley (1987).

3.2.7 Assessment of people with different levels of functioning: health status versus quality of life

There is disagreement in the literature as to the correct use of the terms health status and quality of life measures. Some authors, for example Ware (1987), argue that the term 'quality of life' has been introduced to distinguish measures from those

which only considered the 'old narrow definitions of health' (i.e. death and disease). This can cause confusion, for in addition to health Ware (1987) proposed that quality of life measures should encompass 'standard of living, quality of housing, the neighbourhood in which one lives and job satisfaction'.

However, Spitzer (1987) suggested that health status and quality of life measures should be used for people with different levels of health. He described a spectrum of health states from perfect health to terminal illness. These are shown in Fig. 3.1.

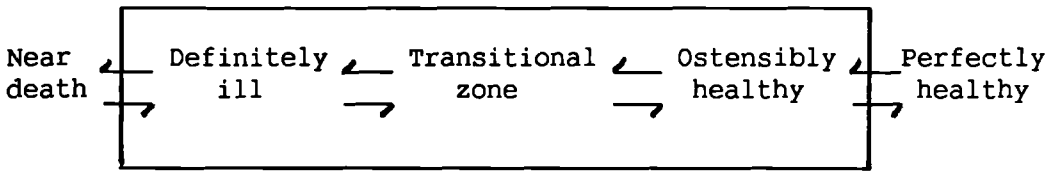


Fig. 3.1 Spectrum of health status states. Source: Spitzer (1987).

The choice of measure depends on the position of those studied along this spectrum. Others support this view. Bowling (1991) notes that when studying severely ill populations, the best strategy may be to employ measures of negative health status.

Spitzer (1987) proposed that health status measures should be 'reserved primarily for assessments of ostensibly healthy people, usually in the context of aggregates of unselected geographically-defined populations or catchment area ..of a service programme'. Measurements of quality of life should be restricted to the assessment of a series of attributes among those definitely sick.

In the transitional zone both types of measures meet and may overlap, alternatively a third type of measures may be needed for this zone (Spitzer 1987).

In practice, Spitzer's (1987) theory has weaknesses. Health status measures are of limited use in healthy populations because they rely on a negative definition of health, as already described. In the general population, health status measures provide little information on 80-90% of general populations (Bowling 1991). To provide information on this large group, the 'perfectly healthy' end of Spitzer's spectrum would need to be expanded, to compare, for example, an athlete and an office worker.

Similarly, problems occur when populations of near death patients are considered. Spitzer (1987) argued that this could be overcome, and that quality of life scales 'can be modified in a minor way to increase discrimination at the end of the morbidity spectrum where people are very sick and in fact are terminally

ill'. The later sections of this review will examine the use of scales in patients near death and consider whether the scales were sufficiently sensitive and where problems occurred.

3.2.8 Measures specifically for cancer patients

Aggressive chemotherapy or other treatments have been used increasingly to treat cancers which are not curable or are rarely curable. Measurement of quality of life in these patients is highly relevant, although reviews of studies have found that frequently quality of life was not recorded or was poorly documented (Clark and Fallowfield 1986).

Cancer is not one disease. There are many different types of cancer, with different presentations, symptoms and prognoses. Nevertheless, scales have been developed to measure health status and quality of life in patients who either have 'cancer' (any type) or who have certain types of cancer (e.g. lung cancer, see Aaronson *et al* 1987).

In a review of 6 measures, Clark and Fallowfield (1986) described their validity, administration and scoring. Karnofsky's (1948) performance status measure is perhaps the oldest, and although this is limited to functional activity (rated 100 = normal, 10 = moribund) it is widely used by clinicians. However, psychological and mental difficulties often accompany illness, and patients with depression and anxiety are likely to show a decline in their enjoyment of life. It is important that measures include the psychological aspects of illness, and the

Karnofsky index is limited because it does not. Measures of general mental health items, such as anxiety, nervousness, positive and negative affect, may not be appropriate for diagnosing specific mental disorders such as depression. This requires separate measures such as interview schedules designed to standardise the diagnosis of selected mental disorders (Donovan *et al* 1989).

Details of some commonly used measures are shown in table 3.2. Many reviews consider the available measures of quality of life and health status, and provide guidance on their appropriate use and analysis. Examples are given in the references, see Maguire and Selby (1989), Donovan *et al* (1989), Aaronson (1991), and Fayers and Jones (1983).

Table 3.2 Selection of some common quality of life, health status and mental health measures used in cancer clinical trials.

Measure	Description
Karnofsky Performance Status scale (KPS) (Karnofsky 1948)	1 item, performance and mobility rated 10 - 100
Eastern Co-operative Oncology Group (ECOG) (Zubrod *et al* 1960)	1 item, performance and mobility (developed from KPS), rated 0 - 4.
Cancer Inventory of Problem Situations (CIPS) (Schag *et al* 1983)	131 problem statements in 4 areas: personal care, medical situation, interpersonal interactions, miscellaneous. Each rated on 5 point scales
Hospital Anxiety and Depression scale (HAD) (Zigmond and Snaith 1983)	14 items in 2 subscales of anxiety and depression. Each rated on 4 point scales.
Psychological Adjustment to Illness Scale (PAIS) (Morrow *et al* 1978)	45 questions in 7 areas: health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, psychological distress. Each rated on 4 point scales.
Spitzer's quality of life index (QL) (Spitzer *et al* 1981)	5 items; activity, daily living, health, support, and outlook. Each rated on 3 point scales.
Rotterdam symptom checklist (De Haes *et al* 1986)	30 symptoms and 8 scales of daily activities in 4 areas: physical toxicity, social functioning, physical activity, psychological adjustment. Each rated on 5 point scales.
Linear Analogue self assessment (Ontario Cancer Institute and Royal Marsden Hospital) (Selby *et al* 1984)	31 items, divided into two groups - general health (18 items) and items specific for breast cancer (13 items).
European Organisation for Research and Treatment of Cancer (EORTC) (Aaronson *et al* 1987).	Self assessment. Core questionnaire for all cancers, extra module for lung cancer. At development and testing stage.
McGill Pain Questionnaire (Melzack 1975).	102 words describing the intensity and quality of pain. Short version with 15 groups of descriptions.

3.2.9 Measures for palliative care

Most palliative care units collect data on aspects of their process of care, such as the number of patients seen, number of home visits, drugs used, duration of survival, and use this in annual reports which are geared towards fund raising (for example see St Joseph's Hospice, 1976). Harper *et al* (1988) conducted a Delphi exercise (Linstone and Turoff 1975), aggregating the views of hospices in the UK, to suggest standards for in-patient and day care units, but this was concerned with the structure and process of care, rather than with outcomes.

Palliative care outcomes have been slow to develop, as these cannot be measured with the usual indicators of mortality or morbidity. They require a measure which includes the specific objectives of quality of life whilst dying, and the quality of dying.

3.2.10 Palliative measures used to date

Studies of palliative care have used a wide range of measures developed by researchers conducting the study, for example, patients' ratings of pain categorised as severe, moderate, mild or absent, the place of care and death, or patient and family anxiety (e.g. Parkes 1979a and 1979b, Hinton 1979, Kane 1984). In some instances satisfaction with care has also been recorded (Kane 1985, Cartwright and Seale 1990). McCusker (1984) developed and attempted to validated scales to measure satisfaction of long-term and terminal care. Measures were not standardised, or pre-tested for validity or reliability (except

McCusker 1984), and tended to reflect the specific aims of the study, rather than the wider aims of palliative care. This was acceptable for research in single settings, but did not allow for multicentre, comprehensive evaluation.

The National Hospice Study, USA, used various measures. Patients were assessed by their carers or family member according to an adaptation of Spitzer's Quality of Life index (the HRCA-QL index), the original and uniscale version of Spitzer's index, the Karnofsky index, the McGill pain questionnaire, an emotional scale, a social scale and an awareness scale, developed by the authors (Greer *et al* 1986, Morris *et al* 1986). Morris *et al* (1986) concluded that the HRCA-QL index was most useful. This index has 5 items: mobility (replacing activity in Spitzer's original index), health, support, daily living and outlook, each rated 0,1 or 2. Spitzer (1981) had expected his QL index to be 'particularly useful in trials of the effectiveness of palliative care or hospice services'. However, Mount and Scott (1983) criticised it for omitting many aspects of care: 'improved communication within the family and between family members and health care workers; lessened uncertainty and fear of the unknown; greater acceptance of the reality facing them; greater ability to express fears, doubts, guilts and anger'. However, they added: 'Until more valid instruments are developed, we must use Spitzer's QL index and the other outcome measures of their study'.

3.2.11 Measuring the 'quality of death'

Scores according to the Karnofsky index and HRCA-QL index deteriorate markedly in all patients towards death (Morris and Sherwood 1987) making these insufficient to measure palliative care. Mount and Scott (1983) noted: " excellence in hospice evaluation must await the development of new outcome measures". The wording of the score definitions is such that if a patient is unconscious he/she will achieve a score of zero in all 5 items (including support and outlook). The index is also only concerned with the patients' condition and not service provision, and only to a limited degree with the support from family or friends.

Existing psychological measures may have similar problems with dying patients. Most measures, for example the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983), or the Beck Depression Inventory (Beck 1979), include items which may not be suitable in palliative care. Questions about feeling slowed down, worrying about the future or irritability could normally achieve positive responses in a dying person.

Wallson *et al* (1988) developed a measure of 'quality of death' by analysing patients' wishes about their death, collected in the National Hospice Study. This data was unsatisfactory because the total sample was biased and included only 11% of hospice patients and an unknown proportion of those receiving conventional care (see section 3.3.2). They analysed interviews conducted with patients in their last three days of life (the number in this category is not given).

After the patient's death, the authors interviewed family members (FMs) to determine which of the 15 most common items had been successfully addressed. Hospice and conventional care were compared. However, there was no attempt to match individual patient's wishes with achievement. For example, only 9% of patients had said they wished 'to be at peace with God', yet over 90% of FMs said that this was achieved. One possible interpretation of this is that some patients who did not wish to be at peace with God had it forced upon them. There is clearly a need to develop measures which can be sensitive to the wishes of individual patients. Most measures of health status and quality of life cannot do this. Measurement is made on an empirical scale which is set for all patients, with the assumption that all patients wish for the highest possible score (e.g. of mobility). However, when items reflect aspects which some people desire and others would not, for example 'peace with God', scales need to allow for the wishes of individual patients and their families.

3.2.12 Who should make the assessments?

Measurement of quality of life may rely on assessments made by patients, their family, external researchers, or by health professionals. All of these approaches have drawbacks.

a) Patients

Taking assessments directly from the person who is dying would seem to give the most valid information. However, this has been criticised mainly for two reasons. First, in some instances it is

considered an intrusion. No detailed evidence is available, but, in one study the relatives reported that they believed dying patients were willing to help in research, often in the hope that this would help others (Mor *et al* 1988c). Fallowfield *et al* (1987) found that most breast cancer patients reported that taking part in a psychological study was a helpful extension to their treatment. Thus, intrusion may not be the problem feared by professionals.

Second, the reliability and completeness of assessments from severely ill patients has been questioned. Ward (1985) and Lunt and Neale (1985) found that, of patients in hospice and home care settings, only one half to one third of patients in care survived and were well enough to be interviewed. Maguire (1980) warned that self-ratings scales may be subject to error: from a wish to give socially desirable answers, a favouring of extreme or central positions on the scale (position bias), or because a far greater proportion of cancer patients than usually realised may have impaired attention, concentration or memory. The National Hospice Study (USA), the largest comparison of hospice and conventional care, included a small proportion of patients receiving care. (This is discussed in more detail in section 3.3.2). If the most ill patients cannot be assessed by interview this is a potential source of bias.

b) Relatives, friends or family members (FMs)

Assessments taken from FMs are necessarily limited to cases where a close relative or friend exists, and will be affected by the

FMs' own process of grief (Parkes 1985). Only a few very recent studies have considered this. Epstein *et al* (1989) tested for correlations between the ratings of 60 subjects and their closest relatives or proxies on scales measuring social activity, emotional status, overall health, functional status and satisfaction. Pearson's r for all 60 pairs ranged 0.43 (satisfaction) to 0.73 (functional status), but if the subjects had below median health, or there was below median subject-proxy contact, or the subjects and proxies lived apart correlations were poor (for example, 0.12, 0.02, and 0.12 respectively for satisfaction). A study comparing the assessments of FMs in the bereavement period showed that these did not correlate with the assessments of patients made during their life (Ahmedzai *et al* 1988). Cartwright and Seale (1990) compared patient and bereaved FMs' (or close friends') assessments of symptoms and services. Mean squared congruence ranged 0.00 (bad temper) - 0.67 (constipation). Relatives tended to be more critical of services and to report more symptoms. The relatives' assessments may be affected in unknown ways by the place of care. Parkes (1985) suggested that relatives may over-report symptoms when patients are at home. It seems clear that, when FMs' assessments are used these must be considered as measuring the FMs' 'pain', 'anxiety' etc. as well as the patients'.

c) External assessors

External assessors can provide an independent view of the patients circumstances, free from many of the biases of

professionals or FMs. However, these may cause intrusion and may interfere with the practice of team members. If the interviewers ask searching questions concerning the patient's insight and future plans they could be replicating or altering the support team's work. The assessments cannot be made 'blind' to the service received, for the patient is likely to refer to their services during interview. When assessing psychological circumstances in interview, an external assessor sees only a very limited sample of a person's behaviour (Miller and Morley 1986).

d) Professionals

Slevin *et al* (1988), Mercier *et al* (1987) and Wilkes (1984) have found that hospital and community staff gave different assessments of quality of life compared with dying patients themselves. Results may be biased by the professionals' own expectations and hopes of a positive outcome. Professionals may be disposed to recall the successful treatments rather than failings (Miller and Morley 1986). However, professionals have the advantage of being able to provide data on all of the patients in their care.

There is clearly no ideal choice. Each study must choose the most appropriate assessor(s) depending upon its aims. The assessments must be validated and the likely biases considered.

3.3 The evaluation of palliative care

A number of evaluations have been undertaken and the following review concentrates on those from the U.K., USA and Canada, where most research is available. The evaluation of bereavement services is not included.

3.3.1 British experience

Single site evaluations

Hospices

Early studies of hospice care focused on individual services and reported their structure and process (e.g. Bates *et al* 1981 or Evans and McCarthy 1984). Such information was often presented in annual reports geared to fundraising (e.g. St Joseph's Hospice 1976). The first formal evaluative studies appeared in the the 1970's. Three research groups - Parkes (1979a and 1979b), Hinton (1979) and Lunt and Neale (1985) - independently showed in-patient hospice care to be more effective than hospital care.

Parkes (1979a and 1979b) showed that bereaved spouses retrospectively reported better pain control, lower patient and family anxiety and distress, and increased satisfaction than matched hospital care controls. Hospice care also costs less. However, Parkes and Parkes (1984) in a follow-up study ten years later failed to show better pain control in the hospice: pain control in hospital appeared to have become as effective.

Using his own interviews with patients and spouses and the reports of a senior nurse, Hinton (1979) found 20 hospice in-

patients to be less depressed and anxious than 20 in an acute hospital ward or 20 in a Foundation Home.

Lunt and Neale (1985), in a comparative study of in-patient hospital and hospice care in Southampton, observed that hospice doctors set more goals for dying patients than did hospital doctors. They believed goal setting was an integral part of good practice, and so, as process evaluation, indicated hospice care to be more effective. However, there were no differences between the two settings in the goals set by nurses, and no outcome measures were used.

Support Teams, home care and out-patients

The results of evaluations of hospice services for out-patients or home care were less positive. Hinton's (1979) comparative study included 20 hospice out-patients who showed less anger than patients in hospital or the Foundation Home but no less depression or anxiety. Although Parkes (1980) initially showed a domiciliary service increased the amount of time patients spent at home and cost less than hospital or hospice care, in 1985 he found that bereaved spouses reported that patients had more pain and anxiety when at home than in hospice or hospital (Parkes 1985).

Multicentre evaluations

The single site evaluations cannot indicated the effectiveness of hospice care more widely, because of variations in hospice

services. The studies of Parkes and Hinton were based on patients at St. Christopher's Hospice, Sydenham, London. This is the pioneer centre for the hospice movement and 'a centre of excellence'. It demonstrates the potential of hospice care rather than the general effect. Multicentre evaluations are much more likely to give a reliable picture of palliative care in the U.K.

The last year of life - a survey of the bereaved

Cartwright and Seale's (1990) study, the Last Year of Life in 1988, gives insight into the effect of hospices (and support teams). This national survey was based on a random sample of 639 adult (aged 15 years or more) deaths registered in England. Interviewers tried to contact the person who could tell them most about the last 12 months of life of the deceased. Seven percent received some form of hospice care (25% of cancer deaths) either in-patient or support team or both (Seale 1991a). These patients were reported to have had better pain relief, greater awareness of their diagnosis and prognosis, and were more satisfied with the services they received (Seale 1991a and 1991b). However, the characteristics of patients receiving hospice care may have been different. There were social class differences, more middle class people had been in private hospitals and hospices than working class people (7% versus 1%, Cartwright 1992).

Support Teams

Other evaluations of support teams have measured only the structure or process of care. Ward (1985) compared nine

domiciliary services in the regions of Yorkshire and Trent in 1985. She showed major differences in their funding (voluntary, NHS or a combination of both), attachment to in-patient unit or free standing, staffing levels and types and especially in their method of working and number of patients per nurse. She explained that the lack of clearly defined criteria for a successful programme made evaluation difficult (Ward 1985 and 1987).

In a stratified random sample of 162 home care and hospital support nurses from 45 different services, Lunt and Yardley (1986) found similar variations in the structure and funding of services. Teams served catchment populations which ranged from 43,000 to 500,000, with variations in the nurse caseload from 11 to 57 current patients per nurse. (One Marie Curie service had 21 nurses, but this worked in a completely different way, not as a support team.) Apart from variations in the number of nurses in a team (from 1-11 nurses), there were variations in the numbers of other members of the support teams: doctors, social workers and in some cases a chaplain, occupational therapist, physiotherapist, psychologist, dietitian, administrator or secretary. Input from other disciplines (including doctors) was less common in the NHS funded teams. There were differences between teams in the aims and patterns of working, and even disagreement within teams and between nurses and their managers on some of the aims of care.

3.3.2 US and Canadian experience

Difficulties in comparison with the U.K

The differences between US, Canadian and British health services may mean that the findings of these studies are not directly transferable (Editorial 1986). The North American provision of home hospice care was either through home health agencies or independent home care units. The latter, especially, are primarily a nursing initiative with variable access to doctors (Mor and Masterson-Allen 1987 and Mor 1988a). In Britain, medical services, even if there are no doctors in the home care team, can be provided by general practitioners.

In contrast to the British findings, the results of North American studies of in-patient hospice care were contradictory, but benefits were demonstrated for home care.

Single site evaluations

Hospices

In New Haven, Buckingham and Foley (1978) found that 35 hospice in-patients and their spouses or main carers had less anxiety and depression and higher social adjustment at interview than 35 matched controls.

Kane et al's randomised controlled trial

One difficulty of all the studies discussed so far is the problem of self selection by patients into either the hospice or control group. Any apparent effect of palliative care may be due to existing differences between hospice and control groups. In

response, Kane *et al* (1984 and 1985), in Los Angeles, carried out the only randomised trial of in-patient hospice care. Patients admitted to the Veteran's Medical Centre were randomly allocated to either hospice or conventional care. One hundred and thirty-seven hospice and 110 conventional care cancer patients were compared. The results were equivocal. Apart from improved patient and family satisfaction there was no significant advantage of hospice care over conventional care in the control of pain or symptoms, activities of daily living, affect, use of therapeutic procedures, number of in-patient days or cost. Equally, hospice care showed no disadvantages over conventional care.

However, during the study 'hospice' patients received both hospice care and conventional care. When the hospice unit was full 'hospice' patients were admitted to general medical wards. Only 60% of the 'hospice' patients died in the hospice, 3% died at home and the rest died elsewhere in the hospital. During the trial 'hospice' patients spent an average (mean) of 13.2 days on general medical wards, not much less than the average (mean) of 20.7 days of the control group. Further, the hospice and general wards were close to each other, so we cannot exclude the possibility that staff treating the 'control' patients changed their management after observing the therapy and practices used in the care of 'hospice' patients. This contamination would reduce the likelihood of finding differences between control and hospice groups.

Support teams

A positive benefit for home care was reported in a randomised trial in 1984. Zimmer *et al* (1984) in Rochester, New York, evaluated one model of home care using a randomised controlled trial. The home care team consisted of a physician, a nurse practitioner and a social worker, who provided 24 hour on-call medical care and nursing and home care services. Elderly patients with either terminal or severe chronic illness were referred and then allocated to either team care or to the usual home health agencies services. Team patients spent less time in hospital, had lower overall costs and more frequently died at home. Satisfaction with care was higher for team patients and their carers than for the control group. There were no significant differences between team and control patients in health status, functional status or survival. Other positive results of home care were reported, although randomised designs were not used (Creek 1982, McCusker and Stoddard 1987).

Multicentre evaluations

Hospices

Hannan and O'Donnell (1984) measured the costs and satisfaction for 12 hospice programmes in New York State. All services cost less than conventional care. Community-based hospices cost less than other units providing hospice beds (either free standing or within existing hospitals). The satisfaction of carers and family was 'high' in all hospices, but was higher for hospices with beds than community hospices.

The National Hospice Study. A study of in-patient hospice, home hospice and conventional care

The National Hospice Study, USA, was devised to demonstrate whether hospice care was effective, so as to consider whether it should receive Medicare funding. The three million dollar project collected prospective data from 40 hospice and 14 conventional care centres; 833 hospice home care (HC), 624 hospice in-patient (HB) and 297 conventional care (CC) patients and their nearest carers were interviewed (Greer *et al* 1986). The hospice patients were less likely to receive therapies such as chemotherapy, surgery, radiation therapy, transfusions and intravenous therapy and significantly more likely to receive social services (Mor *et al* 1988a). Home care hospice patients spent more time at home (Mor *et al* 1988c).

There were few differences in quality of life outcomes measured between conventional care and hospice care. Some small but significant differences were found to the benefit of HB but not HC patients in pain, symptoms and satisfaction of family members. However, there were no consistently observable differences between hospice and non-hospice patients in performance status, quality of life, or satisfaction with care as reported by patients' families (Greer *et al* 1986, Morris *et al* 1988).

The results of cost savings were mixed. Home care hospices saved money over conventional care by substituting care at home for hospital care. The savings occurred mainly in the last months of

life, and for both HB and HC patients the longer the stay in hospice, the more likely the costs incurred exceeded those of conventional care patients in the last year of life (Kidder 1988a and 1988b).

The National Hospice Study: sample bias and other difficulties

Sampling inconsistencies limit the conclusions of this study. In the sampling procedure there are three problems (see Mor 1988a and 1988b, Greer *et al* 1983 for details of the study design). First, the main sites of the conventional care group were not representative, since the criteria for inclusion in the conventional care group and the hospice group differed. Conventional care units were probably better than average due to their four extra selection criteria of good records, follow up, willing doctors and nurses and proximity to regional centres. Second, the criteria for selection of patients differed in conventional care and hospice care settings. In conventional care settings patients with a low mobility were actively selected (Karnofsky score of 50 or less), there was a much higher refusal rate (20.6% compared to 3.3% and 3.5% in the hospice settings) and patients were selected in conjunction with the oncology nurse clinician. In addition, the physician was asked for permission to contact the patient. The authors do not state the number of cases in which the oncology nurse or physician objected to the contact. Third, we cannot say whether patients were selected fairly or not, since no details are given of the full conventional care denominator populations. In the hospice

group from an initial denominator of 13374 patients, only 1457 (11%) were interviewed. It is not clear what proportion of patients died before they could be interviewed, were too ill for interview, or were selected out by the staff or by random selection.

3.4 Summary of main findings from literature

The literature shows the value of measuring health outcome, rather than structure or process. A wide variety of health status and quality of life measures are available, but these do not address the goals of palliative care for patients and families, and are not sensitive to changes in dying patients or to individual wishes. Although there have been many evaluations of palliative care, these were limited by the lack of measures, by variations in palliative practice and by their research design. Future evaluations should concentrate on determining where improvements are needed, and which components of care are effective in which patients. But such evaluation needs measures of the specific goals of palliative care. This thesis attempts to tackle the task of developing measures, using the available guidelines for their development.

4. METHODS: GENERAL

4.1 Role for audit

4.1.1 Summary of difficulties in the evaluation of palliative care services to date

1. Lack of available measures

This was discussed in the previous chapter. Palliative services need ways to monitor their care if they are to improve patient care and find the best mode of working. In most clinical practice a patient's blood pressure, pulse etc., are measured, but in palliative care this is rarely appropriate. The lack of valid sensitive measures for palliative care has hampered research to date. These types of measures are required before future evaluations can be carried out.

2. No Standard Practice

Services, particularly for home care, operate in many different ways. As described, major differences have been found between different hospices or support teams in their structure and process. This limits the conclusions which can be drawn, negative or positive results can be attributed to the characteristics of individual services, rather than to the 'palliative' effect. There is an urgent need to clarify the goals of palliative care, and then to measure whether these goals are widely achieved.

3. Palliative care embodies a number of different interventions.

Palliative care is provided by various professionals and volunteers, in multiple settings, amidst a complicated network of

patient and family variables, and have closely interrelated goals that seek integrated "holistic" palliative care (Buckingham and Lupu 1982). It subsumes a complexity of palliative interventions, just as surgery has many factors which have never been tested in one study as one intervention (Dush and Cassileth 1985).

Given the wide variety of services, we need to know for which patients palliative care is most effective and which models of care work best. Rather than posing the global question is 'palliative care effective?', an equally important question would seem to be what kinds of palliative care interventions, by whom, in what combination, form and amount, for what kinds of patients and families, and with which types of concerns, work best under a particular set of circumstances (Dush and Cassileth 1985)?

4. Difficulties in research design

The World Health Organisation defines evaluation as: 'the systematic, scientific method of determining the extent which an action or set of actions was successful in the achievement of predetermined objectives'(Hogarth 1975). Much evaluation in health care has relied on randomised controlled trails to assess efficacy (the benefits to individuals of a procedure applied under controlled and usually ideal conditions). However, these have been used only occasionally to evaluate palliative care. Possible reasons for this include:

a) the influence of voluntary groups in generating funding and

providing services. Voluntary groups are more likely to be influenced by local concerns and difficulties than by a wish to meet rigorous evaluation criteria.

b) the ethical issue of informed consent. Can patients be asked in their final months of life to agree to a random allocation between a service and no service? In the National Hospice Study random allocation was considered 'unethical' (Aiken 1986). In London, before this study, local general practitioners were asked if they would participate in a randomised trial of a support team. Most refused, they felt they could not confidently persuade patients to agree to a support team being involved in their care if the patients then might, or randomly might not, receive the service.

c) the evidence that conventional care was failing patients. Political pressure for palliative services led to the decision to make hospice care reimbursable under US Medicare Legislation, before the results of the National Hospice Study were available (Mor *et al* 1988c).

d) contamination of controls. Mount and Scott (1983) have argued that it is unlikely the control or customary care group will truly represent the traditionally neglected terminally ill, simply by virtue of their study inclusion. Any identified control group will have been subject to the "educational effect of hospice care", which was deemed responsible for the lack of difference between hospice and conventional care by Parkes (1985) and Kane *et al* (1984).

4.1.2 Future needs for study

The evaluations to date show that hospice care is viable and in some studies, is an improvement on and cheaper than conventional care. It has been argued that in a pluralistic society such choice is justified on its own merits (Greer *et al* 1986).

The research evidence suggests that evaluations in the future must look at ways of improving palliative care, at its effectiveness (the benefits of care at a population level) and at testing the efficacy of specific interventions. Before any of these can proceed better measures are required.

4.1.3 Role for audit in the evaluation of palliative care

Definition of audit

The Department of Health (1989b) publication Medical Audit defines medical audit as: 'the systematic, critical analysis of the quality of medical care, including the procedures used for diagnosis and treatment, the use of resources, and the resulting outcome and quality of life for the patient'. All doctors in the National Health Service are now required to undertake medical audit, as part of the National Health Service review (Department of Health 1989b), and audits of hospital and general practice are regularly published.

Shaw (1980) provided a variety of other terms for audit, see table 4.1.

Table 4.1 Audit by any other name. Source: Shaw, 1980.

Medical	Care	Evaluation
Health	Standards	Assessment
Clinical	Activity	Assurance
Professional	Quality	Audit
		Review
		Monitoring

Quality assurance and audit are sometimes confused, but most researchers (for example Shaw 1989 and Black 1990) consider audit as one component of quality assurance. Quality assurance is defined by Shaw (1989) as the 'definition of standards, the measurement of their achievement and the mechanisms to improve performance'.

Audit is a cycle. At the outset standards are set. The practice is observed, and compared with the standards, following which changes are made to reach the standards (Shaw 1989, Royal College of Physicians 1989). The cycle is then repeated with the same standards or with new standards developed from the practice. Variations of the original cycle have been proposed: for example, including a preliminary stage of observing practice before standards are set (Coles 1990).

Medical audit has developed in general practice and hospital settings where doctors usually lead the decision making (Sheldon 1982). In community care, doctors often work in teams, sharing the tasks of assessment and decision making with other professionals. Clinical audit is more appropriate to review this type of work. Although defined in similar terms, clinical audit is the systematic, critical analysis of the quality of clinical care, rather than of only medical care (Shaw 1980). Clinical audit by community teams needs performance to be recorded by all members of the team, using broad measures that capture the full range of clinical tasks.

Benefits of clinical audit in the evaluation of palliative care

Clinical audit gives a service the opportunity to develop ways of looking at and measuring their work, and the quick feedback of results is likely to improve their co-operation. If suitable outcome measures are used by services in clinical audit, areas where the service is least effective can be identified leading to changes and improvements in practice. Differences in outcome between patients with different characteristics (e.g. diagnoses) can be shown. Therefore, the outcome measures developed in this work were geared primarily for use in clinical audit. The discussion considers whether they are suitable for wider use.

4.2 Developing measures and testing validity and reliability

4.2.1 Standards for developing measures

Various methods have been used to develop measures of health status and quality of life, but more recently guidelines been suggested (Streiner and Norman 1989, Spitzer 1987, Ware 1987). A number of stages, each employing different methods are needed.

a) Determine that no other available measure can be used

The increasing number of available measures makes it important to review the literature to determine whether existing measures can be used (Streiner and Norman 1989). Various critical reviews of measures are available (see Bowling 1991, Maguire and Selby 1989, Morris 1991 and see literature), although only one considers palliative care (Fallowfield 1990), and this describes issues rather than palliative measures. Measures should be

assessed according to their face, content and criterion validity, their reliability and, if appropriate, their contruct validity (Streiner and Norman 1989). Practicality (whether the scale is suitable for use in ordinary practice) and utility (whether the scale is able to produce useful results) need to be added to this list of criteria, if the scale is used in audit. If no measures are suitable, as demonstrated for palliative care, then new ones need to be developed using the following guidelines.

b) Devise the items and select ones to be included. This can be carried out using a combination of: clinical observation, theory, research findings, expert opinion and consultation with patients, their representatives or a sample of the general population. Streiner and Norman (1989) describe clinical observation as potentially the most fruitful, but Hunt *et al* (1986) and Bowling (1991) have noted how seldom patients views are considered in constructing measures. This study used clinical observation, consultation with professionals and a few patients and bereaved relatives, and literature review.

Items should be selected according to their ease of interpretation, considering the reading level of the respondents, and should avoid ambiguity, double questions, jargon and value-laden words (Streiner and Norman 1989, Boyle and Torrance 1984) following guidance on wording, such as that by Oppenheim (1966).

c) Determine face, content and consensus validity at this early stage. The validity of a scale is assessed by determining its

success in measuring what it sets out to measure. There are various types of validity (see table 4.2 for definitions).

Definitions sometimes vary. Face validity is defined here (as by Streiner and Norman 1989) as whether the scale appears to be assessing the desired qualities. Abramson (1990) argues that some degree of face and content validity are *sine qua non*, and without these there is no point in proceeding to other stages. Face validity should never be treated as trivial, for if respondents fail to take the measure seriously the results may be meaningless (Rust and Golombok 1989). However, Cronbach (1990) proposes that content validity, exploring the suitability of items in detail, is more important than face validity.

Items should be pre-tested to ensure they are understandable to the target population (Spitzer 1987), are unambiguous and ask only a single question. Items not meeting these criteria should be eliminated or rewritten. Items should be added or discarded to satisfy content validity (Streiner and Norman 1989)

Table 4.2 Definitions of basic terms in validity. (Compiled from definitions given by Streiner and Norman (1989), Bowling (1988), Abramson (1990), Moser and Kalton (1971), Cronbach (1990).

Term	Definition
Validity	- The success of a scale in measuring what it sets out to measure
Face validity	- Whether the scale appears relevant, reasonable and is acceptable to those using the test.
Content validity	- The items should contain the common thread of what is under study and sample all the relevant or important content or domains in a balanced way.
Consensus validity	- When a number of experts agree measurement is valid.
Criterion validity	- Whether there is a correlation between the measure under consideration and another measure or event which is suitable for use as a criterion of validity (a gold standard). The best criterion is one which has higher face validity than the measure being tested and/or which has been tested previously and found to be of high criterion validity (see Abramson 1990). Criterion validity can be tested concurrently (concurrent validity) or by the accurate prediction of future events (predictive validity).
Construct validity	- On the basis of theoretical considerations the researcher postulates the types and degrees of associations between the scale and other variables, and then examines these associations to determine if they confirm the expectations (see Moser and Kalton 1971) Construct validity is needed when gold standard measures are not available to test for criterion validity. This is common when attempting to measure something which is not readily observed, such as anxiety or some symptoms (see Streiner and Norman 1989)

d) Scale responses. Response scales may be nominal, ordinal, interval or ratio, depending upon the attribute considered. Clearly ratio and interval scales are difficult to apply to health status. Ratio scales require a meaningful zero point which cannot be found in health status. Some methods have been devised to achieve apparent interval-level measurement with subjective scales (Streiner and Norman 1989), but these are relatively rare and complicated. Such techniques would not be needed for palliative care. It would be sufficient to identify those patients who fare poorly according to agreed criteria, without determining exactly how much worse they fare compared to other patients.

McKelvie (1978) investigated the reliability and validity of a continuous and various categorised (five, seven, 11) rating scales. He recommended scales with five or six categories because these were most reliable, and subjects, even when using the continuous scale, operated within five or six categories.

e) Determine practicality and utility. Boyle and Torrance (1984) proposed that, to maximise its usefulness, a scale must be simple to apply, acceptable to its respondents, brief and inexpensive to administer. It should not require prior access to or use of clinical or laboratory services. It should reflect good measurement practice and efficiency, by using pre-coded response categories, an explicit time period of assessment (e.g. today, the last week or month) and clear unambiguous instructions for respondents.

f) Ensure and test criterion and construct validity

Criterion validity

Criterion validity tests measures which have already been shown to have face validity against 'gold standard' or absolute scales of the underlying construct to be measured (table 4.2). However, there are no gold standard measures of palliative care. In the absence of a gold standard, Abramson (1990) advises that a criterion with a higher face validity is chosen.

Patients are the most valid assessors of their circumstances and therefore can serve as a criterion. Assessments from family members (FMs) have been frequently used as a proxy for the patient's assessment. Although, as shown in the literature review, the validity of FMs as patients' proxies is not established, it is still useful to include their assessments as a potential criterion. Furthermore, a palliative measure should include items which assess the FM's problems, because FMs are included in palliative care. For these items FM assessments have validity.

Therefore, ratings completed by team members, when using the developed measure to audit their work, were compared with:

a) Ratings made by patients, collected at research interview and

b) Ratings made by FMs, collected at research interview

Construct validity

Construct validity refers to a wide range of approaches and is

used when gold standard measures are not readily available and the variable of interest in not easily observed (table 4.2). This approach has been used frequently in psychological testing and is relevant to palliative care where the quality of dying is not easily observed. Construct validity tests for correlations between two instruments according to pre-determined hypotheses. The danger of construct validity is that is tests the hypotheses as much as the validity of the new scale (Moser and Kalton 1971)

Construct validity can be divided into convergent validity, which requires the new measure to correlate with related variables, and discriminant and divergent validity, which requires the new measure not to correlate with dissimilar variables (Streiner and Norman 1989, Bowling 1991). Spitzer (1987) advocates that both should be demonstrated.

'Silver standard' index of quality of life - the HRCA QL-Index

The HRCA-QL is a modified version of Spitzer's quality of life (QL) index. Spitzer *et al*'s (1981) QL-index has five components, activity, daily living, health, support and outlook, each rated on 3 point scales (0-2); with a high score indicating the best condition (appendix H shows details). In the HRCA-QL, the item 'activity' was replaced by 'mobility' (Morris *et al* 1986 and 1988). The HRCA-QL was not re-validated, but the original QL-index was validated. This showed convergent discriminant and content validity among cancer patients (the common cancers, in

four stages; early, stable, rapidly evolving and advanced) and patients with chronic diseases (irreversible or disabling disease such as rheumatoid arthritis, advanced diabetes, spinal injury or chronic obstructive airways disease). Assessments of internal consistency demonstrated a 'high' Cronbach's alpha (0.775) for a five item scale. 'High and significant' interrater Spearman rank correlations were found when the independent scores of two physicians were compared (rho = 0.81, $p < 0.001$), and when doctors ratings were compared to the self-ratings of patients (rho = 0.61, $p < 0.001$) (Spitzer 1981). The HRCA-QL was therefore the most appropriate 'silver standard' measure for validation of a new measure of palliative care.

g) Ensure and test reliability

Reliability refers to the stability and consistency of information provided by the measure, also sometimes referred to as the precision of the measurement (Nunnally 1970, Streiner and Norman 1989). It is reflected by the repeatability of measures. A measure is reliable to the extent that repeated measures under constant conditions will give the same result. The reliability coefficient (or coefficient of generalizability) is the theoretical correlation between the true result from the test and the result from the test achieved by normal use when measurement error occurs (Nunnally 1970).

Reliability is also important in setting a limit on the levels of validity which can be found. If a measure is valid it must also be reasonably reliable and any correlations found in testing

validity will be reduced by the degree to which the measure is unreliable. However, a measure can be reliable without being valid (Carmines and Zeller 1979).

Three methods of testing reliability are used.

i) Test-retest reliability

For this the test is applied to the same population on two occasions and the results are compared, usually by correlation (Streiner and Norman 1989).

ii) Multiple/alternative form reliability

In this scores from two measures, which have been developed in parallel to assess the same attribute, are tested for correlations. High correlations indicate high reliability (Streiner and Norman 1989, Bowling 1988). However, this test is practically difficult and expensive, because it requires that two measures are developed when only one will be needed.

iii) Internal consistency

This considers the homogenicity of the measure. This approach assumes that the complete test reflects some single trait. For example some IQ tests, where all items of the test are reflecting the underlying trait - the person's intelligence. Scores from combinations of the items in the measure, usually one half versus the other half, are tested for correlations. In theory, if the measure is homogeneous the halves can be

considered approximations to alternative forms. Thus, the analysis gives an estimate of reliability. But internal consistency is reduced if the scale is not totally homogeneous and items within the measure record different attributes which do not increase and fall together (Carmines and Zeller 1979, Cronbach 1990, Nunnally 1978).

The palliative measure (STAS) would be expected to reflect the underlying concept of quality of care whilst dying and quality of death. However, each item may represent a discrete entity and would not necessarily correlate strongly with the other items. Very high levels of internal consistency would not be desirable because STAS aimed to measure several attributes of palliative care. Nevertheless, the results from two approaches to test internal consistency, split half reliability and Cronbach's alpha, reflect the value of the total measure, and its reliability.

Split-half reliability

In split-half reliability the items are randomly divided into two sub-scales which are then correlated with each other. The easiest split is to put all the odd numbered items into one half, and the even numbered items into the other. If the scale is internally consistent the two halves should correlate highly.

The resulting correlation is an underestimate of the scale, since the reliability of the scale is proportional to the number of

items in it. Since the sub-scales being correlated are only half the length of the version that will be used in practice, the resulting correlation is too low. The Spearman-Brown formula is used to correct this as follows (Cronbach 1990):

$$r = \frac{2\ rii}{1 + rii}$$

where: r = reliability coefficient for the whole test

and rii = reliability coefficient for half of the test.

Cronbach's alpha

There are two difficulties with split half reliability. First there are many ways to divide a scale other than an odd / even split. Second, it does not tell us which item(s) may be contributing to low reliability. Cronbach's alpha gives an average of all the possibilities of split half reliability of a measure (Streiner and Norman 1989, Cronbach 1990). Alpha is considered a unique estimate of the expected correlation of one measure with an alternative form containing the same number of items. Nunnally (1978) has demonstrated that alpha can also be derived as the expected correlation between an actual test and a hypothetical alternative form of the same length, one that may never be constructed (Carmines and Zeller 1979).

Cronbach's alpha is calculated based on the formula (Cronbach 1990):

$$\text{alpha} = \frac{k}{(k-1)} \left(1 - \frac{\text{Sum } s^2_{\text{items}}}{s^2_{\text{total}}}\right)$$

where: k = the number of items in the test

s^2_{total} = variance of the totalled ratings (of all items in

the test)

s^2_{items} = variance of each item's ratings.

Novick and Lewis (1967) have demonstrated that, in general, alpha is a lower bound to the reliability of an unweighted scale of N items. It is equal to the reliability if the items are parallel. Thus, the reliability of a measure can never be lower than alpha, even if the items depart substantially from being parallel measurements. In most instances alpha provides a conservative estimate of reliability.

The formula indicates that the value of alpha depends on the average inter-item correlations and the number of items in the measure. Therefore, the addition of more items in the measure, which do *not* result in a reduction in average inter-item correlation, increases the internal consistency of the measure.

Enhancing reliability

Reliability can be enhanced by using the measure in controlled conditions, by ensuring that assessors are adequately trained, by using unambiguous items, and by providing unambiguous rating instructions (Moser and Kalton 1971).

Spitzer (1987), in his minimum criteria for validity and reliability, proposes that reliability and validity should be tested with the types of patients and respondents among whom the measure will be used.

4.3 Study setting

4.3.1 Five study teams

Recruitment of teams

Five palliative support teams, all based in the south-east of England, took part in the study. Criteria for inclusion were:

1. Team management and team members were willing to participate.
2. Teams were based within travelling distance of less than 1.5 hours from the research base in London and total travel costs would be within budget.
3. The five teams would include community and hospital based teams, if possible with different methods of funding and different staff, to reflect the variety of structures available.

Characteristics of the teams

Similarities: aims and supportive role

Palliative teams have been described in the literature (section 3.1.3, and see Bates *et al* 1981, Ward 1987, Evans and McCarthy 1984). However, some key characteristics of the five teams in this study are summarised here.

The five teams all followed the philosophy of the hospice movement and of palliative care. Even when teams were not funded by the National Health Service (NHS) they worked with NHS services in the same way as NHS funded teams. Referrals were accepted from hospital staff and general practitioners in all teams, and also from district nurses and social workers in two

teams. Teams provided extra support, advice and shared care with other services.

Team members visited and advised on in-patients although the original hospital consultant remained in charge of in-patient care. No team had in-patient beds for their own use, but all teams liaised closely with and would arrange for admission into local hospices or the hospital as the patient wished.

Teams could reduce out-patient attendance by offering closer home monitoring, but visited patients at home only if their general practitioner agreed. The general practitioner and community nurses were expected to remain involved in the patient's care and offer 24 hour on-call care.

Differences: in structure, process and catchment populations

Each team had a slightly different structure and there was no consistent pattern. Tables 4.3 - 4.5 show details of the staffing, funding, throughput and area served. Teams B and E were the largest, with 6.5 and 5.5 whole time equivalent (wte) salaried team members respectively. Teams C and D were the smallest, and included only nurses supported by other staff. The referrals per wte team member (medical, nursing and social work) ranged from 33 (team C) to 50 (team D) patients per year. These figures are based on team reports.

Teams B, C and D were hospital based, teams A and E were community based: sited in the grounds of their local district

hospital and managed by community services or independently. In four teams, all except B, all staff worked in the community and in hospital. Team B had found it easier to have two nurses working solely in the community and two nurses and the social worker working solely in the hospital. Their doctor saw patients in both settings. At the time of entry into the study one team (B) offered day care, but recently team E has also developed day care facilities.

Teams A, B and E provided a 24 hour on-call service for patients and families at home, and for community and hospital staff, and would visit out of hours if necessary. The smaller teams (C and D) did not offer this service, although the nurses sometimes gave their home telephone number to patients and families if they felt this was necessary. All teams had been established for over one year, date established ranged 1978 - 1986. Three were based in inner London, one in a New Town (C) and one in outer London (E).

Table 4.3 Staffing of the five support teams.

Team	S T A F F I N G (wte equivalent)					
	Nurses	Doctors	Social Workers	Secretary/Admin	Volunteers	Other
A	2	0.6	1	1	4	Consultant attached
B	4	1	0.5	1	0	Consultant + chaplain attached
C	3	0	0	shared	0	Medical support from hospital
D	2	0	0	shared	0	Medical support from hospital
E	3	1*	0.5	1	30+	Volunteer co-ordinator

* A clinical assistant plus a medical director

Table 4.4 Funding, base, area served and referrals of the five support teams.

Team	Funding	Base	Area served	Referrals per year(approx.)
A	NHS	Community Unit*	Inner London	160
B	NHS	Teaching Hospital	Inner London	200
C	NHS **	District Hospital	New Town	100
D	Macmillan	Teaching Hospital	Inner London	100
E	Voluntary/NHS	District Hospital*	Outer London	200

* Both teams based in grounds of hospitals (team A - teaching, team E - district). Team A was managed by the community unit, team E was independently managed.

** Initially funded by Macmillan (Cancer Relief Fund).

Table 4.5 Population and mortality of the local health districts of the five support teams.

Team	D E M O G R A P H Y I N T E A M S' L O C A L H E A L T H D I S T R I C T S						
	P O P U L A T I O N *					M O R T A L I T Y **	
	Females	Males	Total	percentage >= 65 years	percentage >= 75 years	yearly from neoplasms n	rate/1,000 pop.
A	67,216	59,434	126,650	16.8	8.1	433	3.4
B	80,519	78,109	158,628	14.2	6.7	473	3.0
C	111,766	109,094	220,860	12.2	5.1	468	2.1
D	79,918	69,723	149,641	14.8	7.2	455	3.0
E	152,517	145,706	298,223	16.8	7.3	817	2.7

* OPCS 1988 mid year estimates: resident population

** OPCS 1988 mortality statistics: resident population

Local Demography and Mortality rate

Table 4.5 shows the populations and cancer mortality of the health districts primarily served by the teams, calculated from statistics provided by the Office of Population, Census and Surveys (OPCS). In addition to the resident populations, all teams advised on in-patients irrespective of their address: this was a large part of the work for the two hospital-based inner London teams B and D. Team E, with the largest health district and the highest number of cancer deaths, worked in half of their district: the remaining area was covered by another team.

Teams A and E (the two community based teams) worked in districts with high proportions of elderly people. The district of A (in inner London) also had the highest mortality rate from cancer. The district of C, a New Town, had the lowest proportion of elderly people and the lowest mortality from cancer.

5. METHODS: SPECIFIC

5.1 Devising items for the measure called the Support Team Assessment Schedule (STAS): observation and literature review.

Items were initially developed through clinical observations and discussion with patients and family members (FMs) during a six month part-time attachment. The work of team A was observed and later participated in, by attending team meetings and by visits to patients, their FMs (including in bereavement), and professionals.

Areas of work were defined first. Objectives of this work were agreed and tested through open discussion with patients and families in the care of team A. An initial list of items, which represented care objectives, formed the "Support Team Assessment Schedule (STAS)". This was amended following further discussion with team A, comparison with the palliative care literature, and discussion with other teams in the U.K. (including teams B and C) and observation of their team meetings. This process aimed to ensure that STAS items made practical sense to the team members, and covered their work in a balanced way.

5.2 Rating scales and definitions.

Further discussions with the team members and review of their case notes identified, for each STAS item, the severity and range of problems encountered. Various types of rating scales, both ordinal and linear analogue, were tested for suitability with the STAS and ease of use by team members. Gradings were developed by

retrospective review of scores on past patients, using case notes, and definitions for score levels for each item were agreed.

5.3 Face, content and consensus validity

For STAS these areas of validity would be satisfied if:

a) For face validity - STAS items would have to make logical sense to palliative clinicians and could be used in clinical practice. STAS should be perceived as yielding information of real relevance to the investigation of palliative care.

b) For content validity - clinicians agreed that the range of their work with patients and families was included

c) For consensus validity - there was a consensus of agreement from clinicians who dealt with dying patients that the items met the criteria in (a) and (b).

To test these, STAS was presented at a series of meetings of hospice, hospital, community, and scientific professionals (listed in appendix A). Also, teams B, C, D and E tested STAS in practice for short periods.

5.4 Initial practicality for intended use: pilot audit

The collection of audit data using STAS was tested with team A to determine what data could be collected, at what intervals and on which patients. The routine team notes were of a high standard

and it was possible to adapt these notes to include the audit.

Study population

All patients consecutively referred to the team over a one year period were included in the audit and were assessed, weekly, according to the STAS and followed until discharge or death.

Data collection

The data collected included:

1. The patients' demographic, social, referral and diagnostic details. (Note, occupation was not recorded, as in testing responses were unreliable: the item was frequently missed, recorded as 'retired' or referred only to the patient's last job.)

2. Discharge and death details.

3. Ratings according to the STAS, recorded at referral and then regularly until death/discharge. A weekly record of patient location (home, hospital or hospice) was also made.

Analysis

The audit data was reviewed and analysed to determine if changes in scores occurred during care and if these could be linked to patient events. Patient trajectories were considered to determine if STAS ratings allowed individual cases to be reviewed over time. The use of the rating scale by the team members was analysed.

The referral and death STAS recordings were analysed using non parametric tests, owing to the ordinal scales and the non-normal distribution of the ratings (Sprent 1989). Wilcoxon's matched pairs signed-ranks test was used to compare the ratings of each item in the first and last weeks of care. The probability level for statistical significance was 0.05.

5.5 Criterion validity of STAS: interviews with patients and family members (FMs)

5.5.1 Study Population

Teams

The study of criterion validity was carried out in two teams, A and E. Both of these are community based teams, working in patients' homes and in the hospital. The teams were chosen because their patients remained in care for longer than those referred to the hospital based teams (median time in care for team A - 7 weeks, for team B - 3 weeks) and would be more likely to be available for interview.

Eligible patients and FMs

Consenting patients at home and in the care of the teams were interviewed. Contact was made after 2-4 weeks of team care to minimise interference with staff work and to allow staff time to develop their relationship with the patient before a new person visited. It was recognised that some patients would be too ill for interview, or might have died before interview. Patients were

not contacted if the support team considered that the patient was too ill. The numbers of and reasons for non interview were recorded.

5.5.2 Method of contacting patients

The methods used to contact patients differed slightly between the two teams, because of team preferences. Team A patients were asked by team members if an external researcher could telephone or contact them by post, to explain the study. Team E patients were telephoned directly by the researcher who had been given a list of patients in care. Patients were asked if they had an FM who would be prepared to assist in the study and separately answer similar questions.

Confidentiality was maintained and patients or FMs not wishing to participate were not contacted again. The patient's general practitioner was notified before the visit, and methods were approved by local ethical committees.

5.5.3 Questionnaire and Interview

The questionnaire included seven STAS items (four patient and family items - 'pain control', 'other symptom control', 'patient anxiety', 'family anxiety': and three service items - 'wasted time', 'practical aid', 'communication between professionals and patient and family'). The number of STAS items was limited because:

(a) the questionnaire had to be kept short for routine use with

ill patients;

(b) the support teams had already found that some items (e.g. 'financial' and 'spiritual') could rarely be assessed after only one contact, and

(c) there were ethical objections to routinely asking patients to assess the items 'insight', 'planning' and 'predictability', as these were potentially distressing.

Two standard questionnaires were used, each dealing with the seven items: one for patients' self-ratings, and the second for FM ratings. Patients and FMs were interviewed simultaneously, but in separate rooms, by the researcher and a trained volunteer. The questions used the same rating definitions as in STAS. The question for pain control (patient's questionnaire) is shown in table 5.1. Appendix F shows the patient's questionnaire in full, appendix G the FM's questionnaire. The questionnaires also included the patient's and FMs views of the team, and their ratings of communication with the team.

Support teams separately recorded weekly STAS ratings on patients from referral to death.

Table 5.1 Patient questionnaire excerpt - patient ratings for 'pain' in the last week.

SYMPTOMS IN THE LAST WEEK

a) PAIN

Have you have any pain? Yes / No

If NO please go on to section (c), if YES please continue

b) What effect did your pain have on you? Please ring one of the below.

0 = none

1 = Occasional or grumbling single or few pains(aches). You are not bothered to be rid of the pain.

2 = Moderate distress, occasional bad days.

3 = Severe pain present often. Activities and concentration markedly affected by pain.

4 = Severe and continuous overwhelming pain Unable to think of anything else.

5.5.5 Analysis for criterion validity

The patient and FM ratings were compared with the corresponding team ratings. FM ratings were also compared with patient ratings: to provide an estimate of the validity of FM ratings. As far as possible, the date of assessment was matched exactly. Patient and FM ratings occurred on the same day, but a team rating may have been made up to 3 days earlier or later than the patient rating. Team ratings were completed on a regular day and time each week; patients and FMs were interviewed on a date and at a time they found convenient.

Severity of items and differences between raters

Median (inter-quartile ranges) ratings, and mean (95% Confidence Interval) ratings, where appropriate for the near normally distributed items, were calculated for patient, family and support team ratings, and Wilcoxon matched pairs signed ranks test was used to test for differences between ratings.

Agreement

The results report the proportion of cases where team ratings were exactly equal to the patient's rating, were within the bounds of +1 or -1 score, and where team ratings fell beyond these bounds. Cohen's Kappa (weighted) was calculated (Bartko and Carpenter 1976, Fleiss 1981). Kappa tests for agreement between pairs of ratings, but corrects for chance agreement. Chance agreement is the agreement that would be observed if two raters assigned ratings at random. Kappa is the most commonly used and recommended coefficient to estimate the agreement

between two raters (Grove *et al* 1981). Weighted Kappa is used when the relative seriousness of different kinds of disagreement can be specified (Fleiss 1981, Soeken and Prescott 1986). This is appropriate for testing STAS. A disagreement of 3 points was considered more serious than a disagreement of 2 points, which was considered more serious than a disagreement of 1 point. The level of acceptable Kappa was set in advance at 0.3 or above - the level used in the development of the QL index (Spitzer 1981). Kappa should be interpreted with caution when most ratings are one score (as for the three service items), as it then gives greater emphasis to the few ratings which do not agree (Spitznagel and Helzer 1985). Few disagreements may be very important in a screening test (Shrout *et al* 1987) but are less relevant in this study.

The analysis was repeated for the team versus FM ratings and patient versus FM ratings.

Correlations

An important test was for correlations between the ratings of different individuals, to determine if one rater reflected another's rating. The data were ordinal but assessments of symptom and pain control and patient and family anxiety were near normally distributed and these four items were tested for both parametric (Pearson) and non-parametric (Spearman) correlation coefficients. However, assessments of the three service items showed a J shaped distribution which could not be transformed to

a normal distribution, and so these were tested using only Spearman correlation coefficients (Siegel 1956).

Probability

A probability of $p < 0.05$ was taken as significant (two-tailed tests except for Spearman correlations which were one tailed, in the light of the positive or negative values of the coefficient).

5.6 Construct validity: STAS compared with the HRCA-QL

5.6.1 Differences between HRCA-QL and STAS

HRCA-QL and STAS measure different things. STAS is geared to solving patient and family problems, for example, symptoms, anxieties and service issues. The HRCA-QL provides a quick assessment of the quality of life of patients ranging from people who are well and recently diagnosed, to those with severe symptoms. Three HRCA-QL items - 'mobility', 'daily living' and 'health' - are geared to living rather than dying. The scores of these items deteriorate as part of the normal process of dying, especially during the last 4-6 weeks of life, the time when patients received palliative care (Morris *et al* 1986 and 1987). HRCA-QL ratings correlate with patient survival (Addington-Hall *et al* 1990).

5.6.2 Hypotheses of construct validity: the nature of correlations between STAS and HRCA-QL

These differences led to the following hypothesis of the circumstances and nature of correlations found (and not found)

between STAS and HRCA-QL:

1. There would be significant negative correlations between STAS and HRCA-QL for items which were similar, i.e. between the patient orientated STAS items (pain control, symptom control, patient anxiety) and the HRCA-QL items, e.g. between 'symptom control' (STAS) and 'health' (HRCA-QL), and between 'patient anxiety' (STAS) and 'outlook'(HRCA-QL). (Convergent validity)

2. There would be few significant negative correlations between STAS items which were concerned with services and HRCA-QL items, because the HRCA-QL does not include service items. (Discriminant validity)

3. Correlations would be greatest for patients early in care, and would be low or nil in patients near death. (In patients near to their death most score 0 for HRCA-QL items, and there is little variance in the scores.)

Correlations would be negative because a deterioration in HRCA-QL is indicated by a reduction in score: a deterioration in STAS is indicated by an increase.

5.6.3 Collection of data

For consecutive patients referred to team A during 17 months, team members recorded weekly assessments according to STAS and to HRCA-QL. The scores were entered into the patient records, first STAS and then HRCA-QL.

5.6.4 Analysis for construct validity

The data was ordinal and in terminally ill patients the HRCA-QL index scores showed a skewed or J shaped distribution (Spitzer *et al* 1981). Therefore, non parametric tests were used. Mean and median HRCA-QL and STAS scores were calculated, and Wilcoxon matched-pairs signed-ranks test was used to test for differences between the scores of patients at referral and discharge or death.

The analysis tested for Spearman correlations between the HRCA-QL and STAS ratings for patients in their first week of care and in the week when death occurred: first, for all patients and then separately, for patients who were in care for more than four weeks before they died. It tested for correlations between a STAS sub-total (summing six items - 'symptom control', 'patient anxiety', 'family anxiety', 'patient insight', 'family insight' and 'spiritual' - all similar in concept to the five HRCA-QL items) and the HRCA-QL total.

A probability of $p < 0.01$ was taken as significant. This is higher than for criterion validity due to the larger sample size anticipated and to avoid type one errors, due to the number of tests performed.

5.7 Methods to test reliability of the STAS

Reliability was tested in two ways, using the test-retest method, and by measuring internal consistency.

5.7.1 Test-retest.

Practical issues and need for simulated patients

Test-retest reliability was assessed by comparing team ratings of the same patients. It was not practical for members of one team simultaneously to assess the same patients, and less so for members of different teams to attempt this. Therefore, written descriptions of patients (simulated patients) were abstracted from team notes, their weekly meetings, and observation of their work. The descriptions often repeated the words of previous patients. Team members recorded STAS assessments based on the information given in these descriptions. An excerpt from one simulated patient is shown in table 5.2. Full details of 10 simulated patients are shown in appendix I. Two data sets were then collected.

Table 5.2 Excerpt from simulated patient no. 20, first four paragraphs.

SIMULATED PATIENT NO.20.

Mrs E. is a 52 year old British widow referred by her general practitioner for support, especially for the 16 year old daughter who lives with Mrs E. in the council house.

Mrs E. presented one month ago with multiple liver secondaries from an unknown primary. She is now deteriorating. She has another daughter and a son, both with young families, and both living within three miles.

When you visit Mrs E. is lying on the bed in her night clothes. She is propped up against a back support because her back aches at times. She is not bothered by this because position relieves the ache. She complains of night sweats as her only symptom. Twice in the last week at night she has had to change the sheets, although she went back to sleep after. During the day she is fine.

She asks you a lot of questions about her illness. She was puzzled that at first the hospital doctors were trying to find her "cancer", but now they had given up. She says she found it difficult to ask them questions. They would answer (rather coldly and factually) if she asked, but they seemed so busy that she didn't feel able to. Her own doctor, although wanting to help, hadn't even been told she was discharged 3 days ago. She had telephoned him and he had been very surprised. He had had to telephone the hospital to find out what medication she had been put on. That meant that for two hours one morning she was on the telephone to the surgery trying to sort out her medication and she found this very tiring.

Test-retest 1.

Pairs of team members, from four different teams, completed ratings on 40 different simulated patients, covering a wide range of problems. The analysis reports the proportion of cases where ratings were equal, and within a boundary of +1 or -1 score, the Cohen's Kappa (pre-set at level 0.3) and Spearman correlations (Bartko and Carpenter 1976, Fleiss 1981, Siegel 1956).

Test-retest 2

Nine team members (2 social workers, 4 nurse specialists and 3 doctors) all completed ratings on five further simulated patients. The analysis calculates the proportion where scores were equal to the most commonly recorded ratings, and the intraclass correlation coefficients (ICC). The latter tested if the variance of the ratings was less than the variance of the scores of different patients (Bartko 1976, Bartko and Carpenter 1976). An ICC above zero indicates that the test is satisfied. The maximum coefficient of 1 is obtained if all the raters agree exactly and the individual patients have different scores.

Significance

In all tests, a high level of significance was set for acceptable reliability : $p < 0.005$ (two-tailed tests: Cohen's Kappa and ICC; one-tailed tests: Spearman correlations).

5.7.2 Internal consistency: split-half reliability and Cronbach's alpha

Data collection for internal consistency

Data collected for construct validity, in section 5.6.3, was used for this analysis. This consisted of STAS ratings and HRCA-QL ratings of patients referred to team A over 17 months.

Analysis

To assess the reliability of STAS at different times in a patient's trajectory during care, split-half reliability, and Cronbach's alpha were calculated for three data sets:

a) all ratings, on all patients, at all stages in care,

b) ratings made on patients at referral

c) ratings made on patients in their week of death.

The reliability of STAS was compared to that calculated for HRCA-QL.

STAS items were entered into the analysis in the order collected by teams.

5.8 Testing the use of STAS: audit of care for the five support teams

5.8.1 Teams and period of audit

The audit was carried out in five cancer support teams A - E (described in section 4.3.1). Consecutive patients newly referred and accepted into care during a minimum six month period, were entered into the study and followed up until death

or discharge. Team A recorded data for 17 months, team B and C for six months each, teams D and E for eight months each. Single episodes of advice, given over the telephone or by a visit, were not included in this audit because teams recorded very few details on these patients.

5.8.2 Data collection

Demographic, social, clinical and death details were recorded as for the pilot study (see section 5.4). The data collected was extended to include details of the patient's accommodation - tenure and mode of access to their home - to provide some information on social circumstances. Details of the main family member or carer included: their relation to the patient, whether they were in full-time employment, part-time employment, no job outside the home, or were retired, and their Karnofsky performance status (Karnofsky *et al* 1948, see appendix H) to indicate their mobility.

To encourage teams to record the information standard clinical records were used, with pre-coded sections. However, to allow teams to maintain their individual identities, the designs of each teams' notes were maintained as far as possible. Appendix K shows the notes for the support teams.

The five teams chose to record STAS ratings at referral and then weekly until death or discharge. The STAS rating forms were generally kept at the back of team notes, so these could be found quickly. The patient's Karnofsky ratings, place of care

(home, hospital or hospice), the team contact and key-worker, were also recorded at referral and then weekly until death/discharge.

5.8.3 Analysis of audit data

Data handling

The data was coded and entered onto a relational data base, Scientific Information Retrieval (SIR), with five records per patient, which had already been designed and tested with pilot data. This system facilitated the handling of complicated data sets, where patients spent varying numbers of weeks in care, and so had different amounts of weekly data. Data was verified and added to the data base in small amounts as it was collected from the teams. The SIR commands perform basic statistical and computing procedures and produce pre-coded files for quick and easy use with statistical packages (e.g. Statistics Package for Social Sciences (SPSSX)).

Characteristics of patients and families in care

The social, demographic, mode of referral, diagnostic and discharge and death characteristics of the patients referred were reported and compared between the different teams and with the OPCS records of mortality from neoplasms in matching areas for matching time periods. Chi-squared was used for the analysis of contingency tables. In the larger tables, if more than 20 percent of cells had an expected frequency of less than five, or if any cells had an expected frequency of one or less,

categories were combined (Bradford Hill 1977). (Burke *et al* 1985 suggested that this rule can be ignored when n > 40. Therefore, any instances where combining categories altered the results were noted.)

Use of STAS by teams

To consider the use of STAS by teams the analysis considers the amount of time patients needed to be in care before all 17 STAS items were assessed. The proportions of late assessments (item missed at first contact but then assessed at a late point in care) and missed assessments (item missed throughout care) were compared for the teams.

STAS ratings during care and the effectiveness of teams

To assess the main problems of patients, the proportions of patients with high and low ratings for the 17 STAS items were calculated. The analysis considered, separately, the majority of patients who remained in care until death, and the minority who were discharged. Ratings for each STAS item were reported for the week of referral, week 2 (2nd week of care), two weeks before death (death-2) and the week of death or discharge. To calculate the ratings in the weeks prior to late assessments the first recorded score for that item was used. Wilcoxon's matched-pairs signed-ranks test was used to test for significant differences between weeks (Siegel 1956).

Data on main symptoms was categorised according to the patient's main symptom for each week. Because the items 'symptom control'

and 'pain control' are near normally distributed, the mean (95% confidence intervals) ratings of these items are plotted, to illustrate changes in score during care (Boneau 1960).

A probability of less than 0.05 was taken as significant, using two-tailed tests.

Total ratings of all STAS items

Teams were asked if they could weight items in order of importance. The properties of a total STAS rating, summing all items, was considered as teams had found this useful in day to day practice. The analysis tested for correlations between individual items and the totalled rating in patients at referral and death, and reports changes in the totalled score during care. Significance for correlations was set at $p < 0.001$ (one tailed tests) - to reduce the change of type one errors due to the number of tests undertaken.

Repeat of internal consistency analysis

The analysis described in section 5.7.2 was repeated on the STAS ratings collected from all five teams. The reliability coefficient, using the split-half method with Spearman-Brown's correction, and Cronbach's alpha were calculated for STAS on all assessments during care, and separately for the weeks of referral and death.

6. RESULTS.

6.1 The Support Team Assessment Schedule - 17 items of palliative care: items, ratings, face validity and initial testing.

6.1.1. Items developed

From the areas of work and literature review, team A initially agreed 14 items of palliative care which represented their goals.

The areas of work identified by teams are shown in appendix B, and included seven areas: assessment, emotional support, co-ordination, advice and education, symptom control, organisation of facilities and bereavement support. Areas of work were relevant to several items, for example the area of work 'organisation of facilities' resulted in the items: 'practical aid', 'financial', 'wasted time' and 'planning'. However, items were not developed for the bereavement work, as STAS concentrated on care before death.

Items and literature of the goals of palliative care

An item 'symptom control' was developed to reflect the goals of palliative care to control pain and physical symptoms (Saunders 1978, Parkes 1979a). The recognition that pain has physical, emotional, spiritual and social components led to STAS including items in these areas.

Items named 'patient anxiety' and 'family anxiety' reflected the goals to support the patient and family, as the unit of care,

both to reduce their anxieties and to support stages of grief, anger or despair (Saunders 1978, Parkes 1979a, Mount and Scott 1983, Mor and Masterson-Allen 1987).

Weisman (1977) defined 'appropriate death' as 'an absence of suffering, preservation of important relationships, an interval for anticipatory grief, relief of remaining conflicts, belief in timeliness, exercise of feasible options and activities, and consistency with physical limitations, all within the scope of one's ego ideal'. Recently, Kellehear (1990) described the features of the modern 'good death' as awareness of dying, social adjustments and personal preparations, public preparations (legal, financial, religious, funeral, medical), work or activities reduced, and farewells. Items of 'patient insight', 'family insight', 'planning' and 'predictability' relate to the later parts of these definitions, and to teams' goals to help patients to achieve as full an understanding of their disease as they wished.

In Britain, the role of palliative care in supporting, advising and educating other professionals is stressed (Working Group on Terminal Care 1980, James 1988). Practitioners identified education needs for symptom control and patient and family support (Haines and Booroff 1986). The items 'advising professionals' and 'professional anxiety' were developed to measure these goals.

The three items dealing with communication were developed because of evidence that palliative care needs good communication. Communication is needed both between all professional staff caring for the dying patient, to ensure liaison and to prevent duplication or delay; and from doctors and nurses, who should give time to communicate with patients and their families rather than withdrawing or appearing hurried or abrupt in their manner. Poor communication is a frequent cause of distress for patients and families (Cartwright *et al* 1973, Maguire and Faulkner 1988a).

Presentations and discussion

The presentations and discussions of STAS suggested that two further items ('spiritual' and 'communication between patient and family') were needed. One item (symptom control) was sub-divided (into pain control and other symptom control) but this was contentious, and not agreed until stages 2 and 3 had begun. It was not felt that any items should be removed. Although staff would have liked a smaller number of items, they could not agree on those which were less important.

Final items

Table 6.1 shows the final 17 items included in STAS and the range of severity from no problem to most severe. The first 10 STAS items are concerned with the needs of the patient and family, and include physical, emotional, spiritual, planning and communication items. The last seven items are concerned with the provision of services, including social, financial, and co-

ordination needs, and the needs of other professionals involved in care. Each definition is termed to show the difficulties as experienced by the patient and family. These seven service items are intermediate outcomes, but nevertheless can have a major impact on the patient and family and are an important part of support team care in the community. For example, after discharge from hospital poor communication between professionals can lead to a general practitioner being reluctant to prescribe drugs for a patient because he/she has not been properly informed by the hospital; or a patient may suffer because community services have not been organised. Teams aim to improve communication between professionals by co-ordinating care.

6.1.2 Ratings

Ordinal rating scales were preferred to a visual analogue scales by staff as this enabled them to define various interim points; they also believed that this would reduce variations between assessments. Seven point (0-6) scales were chosen for the pilot study as it seemed to the team that these best reflected the detailed assessments they made. However, when piloted severe scores for the service items were seldom recorded, so subsequently scales had five points (0-4).

High scores indicated high levels of patient need, low scores indicated low needs; table 6.2 and 6.3 show the complete ratings the items 'pain' and 'practical aid', appendix C shows the ratings for all items.

Table 6.1. Definitions of the 17 items in the Support Team Assessment Schedule (STAS)

ITEM	DEFINITION	RANGE best - worst
Pain control	Effect of pain(s) on the patient.	None - severe and continuous, unable to concentrate, eat, sleep or describe.
Symptom control	Effect of symptom(s) on the patient.	None - severe and continuous, unable to concentrate, eat, sleep or describe.
Patient anxiety	Effect of anxiety on the patient.	None - severe and continuous, unable to concentrate, sleep or describe.
Patient insight	Patient's knowledge of his/her prognosis.	Full knowledge of prognosis - not knowing he/she has cancer.
Family anxiety	Effect of anxiety on the family*.	None - severe and continuous unable to concentrate, sleep or describe.
Family insight	Family's* knowledge of prognosis.	Full knowledge of prognosis - expecting to become completely well.
Predictability	Patient and family's* need to know likely future events and time scale related to the team's ability to provide this information.	Future events clearly predicted or stable - no idea of likely disease progression and future arrangements.
Planning	Further need for the patient, as desired, to organise his/her affairs and special meetings.	Completed or unnecessary - major decisions outstanding, patient at a loss where to begin.
Spiritual	Effect of any crises in beliefs, faith or religious practices on the patient.	Content in own beliefs - distraught with uncertainty or guilt, and in chaos how to resolve this.
Communication between patient and family	Depth and openness of communication between patient and family*.	Communicating openly and honestly - both pretending.
Practical aid	Further need for practical aid at home reflecting the difficulty for patient and family* without aids.	None needed - patient incapacitated without basic aids.
Financial	Further need for benefits reflecting the difficulty for patient and family* without benefits.	No benefits due - many entitled, patient and family with no money and in chaos.
Wasted time	Amount of patient's time lost for tests which could have been avoided, the patient not wishing to attend.	No time lost - several days wasted.
Communication professionals to patient and family	Depth of information given to patient and family*, when they require this, from other professionals**.	Full information with any changes explained - avoiding answering all questions and visiting.
Communication between professionals	Speed, accuracy and depth of information communicated between other professionals** reflecting any difficulties for patient and family*.	Correct messages to all involved on the same day - no communication or idea of who else is involved.
Professional anxiety	Effect of anxiety on other professionals** reflecting any difficulties for patient and family*.	None - overwhelming anxiety with inappropriate action.
Advising professionals	Amount and speed of advice needed for other professionals.	No advice needed or previous advice implemented - major difficulties unrecognised by key workers.

* *Family = the patient's nearest carer.*

** *Other professionals = the other involved professionals including: General Practitioner, District Nurse, Social Worker, Hospital Staff.*

Table 6.2 Definition and ratings of STAS item pain control.

Pain control = Effect of his/her pain on the patient.	
RATING	DEFINITION
0 =	none
1 =	Occasional or grumbling single pain. Patient is not bothered to be rid of symptom.
2 =	Moderate distress, occasional bad days, pain limits some activity possible within extent of disease
3 =	Severe pain present often. Activities and concentration markedly affected by pain.
4 =	Severe and continuous overwhelming pain. Unable to think of other matters.

Table 6.3 Definition and ratings of STAS item practical aid

Practical aid = Further need for practical aids at home, reflecting the difficulty for patient and family without aids.	
RATING	DEFINITION
0 =	None needed.
1 =	One aid desirable, not urgent, patient managing at present.
2 =	One aid needed urgently ie. the next day, or a few aids needed soon, patient or family experiencing some difficulty.
3 =	Aids needed badly, some improvisation possible.
4 =	Patient incapacitated without basic aids.

6.1.3 Missed, late and not applicable assessments

Staff were allowed to miss item ratings until they could make a 'late' assessment. This was likely to occur for some patients for items such as 'insight' and 'financial' when the team member might not wish to enquire too deeply until after two or more visits. Occasionally items were missed throughout care, if the team members were unable to discuss the item with the patient or family. These assessments were classified as follows:

a 'late assessment' = the item was missed at first contact, but was assessed at a later point in care;

a 'missed assessment'= the item was never assessed during care.

To calculate the total score for all STAS items in the weeks prior to late assessments the first recorded score for that item was used.

A rating of 'not applicable' was recorded for family insight and family anxiety if the patient had no family or carer who could be assessed. Not applicable ratings were omitted from the analysis.

6.1.3 Timing and frequency of assessments

Most teams hold weekly review meetings of patients and families in care. The most efficient method of recording STAS ratings was at these weekly meetings, rating the condition of the patient and family over the past week. This ensured that team members did not forget a recording, and enabled them to discuss the assessment with other team members. However, patients sometimes varied in their condition from day to day. When this occurred team members found it difficult to estimate ratings over the

whole week. More frequent recording was tested and found to be too time consuming and unpopular. Therefore, some of the STAS definitions were adapted to take account of a patient's average condition over the week (e.g. number of days where a problem had occurred). Team members learned to estimate average conditions, although they continued to express some frustration that the STAS did not detect variations in condition from day to day.

6.1.4 Results of pilot study and testing in other teams: practicality

STAS was used successfully for one year and applied to all patients in the care of team A. The team found STAS applicable and suitable for practice. Each patient and family was assessed weekly, at the team's meeting from referral to death. Results from the pilot study are shown in appendix D and E. The study was successful in identifying items which the team rated as most difficult to achieve and cases where the team scored themselves as not effective.

Time taken to completing ratings

STAS was incorporated into the teams' work. It took staff between 30 and 90 minutes, at the weekly meetings, to record the scores on all their current patients (10 - 25 patients for each team member). Most time was spent on the assessment of new patients, since the team member would usually discuss this with colleagues. Thereafter, rating a patient who was stable and had been in care for several weeks would take only a minute or two to

complete. Twenty STAS ratings (including 5 first assessments) were timed; the median time to complete a rating was 2 minutes (range 1-15).

It was initially proposed that team members would jointly discuss and score each patient and family during the weekly team meeting. This was tested in teams A and B and was found to be not practical, taking over 2 hours to record assessments for a full caseload.

Many patients kept the same key team worker throughout care and so each week the same team member was responsible for completing the STAS ratings. When two or more team workers were involved they discussed and agreed the ratings.

Value of completing ratings

Staff reported that STAS ratings helped them to clarify the main problems of a patient and decide on the urgency of their intervention. Late assessments alerted them to the fact that they had not assessed this aspect of care and encouraged them to do so. Often, the recording of a patient's STAS rating would remind the team member to organise some aspect of care or to liaise with other professionals, which they would attend to before continuing to record the STAS rating for their next patient.

Staff reported the greatest difficulties in assessing the item

'predictability'. This was described as a factor which was important for patients but difficult to quantify.

6.2 Criterion validation of STAS, against assessments from patients and their FMs

6.2.1 Patient and FM interviews

A total of 183 patients was contacted for interview: 117 referred between January 1987 and November 1987 to team A and 66 referred between January and end May 1988 to team E. Eighty-four patients were interviewed at least once; 99 (54 %) referred patients could not be interviewed, usually because they had died (table 6.4). Team E had a slightly greater percentage of refusals, most commonly due to the FMs refusing. This difference is partly explained by the type of approach used for interviews. Requests for interview were made by the team members in team A, but over the telephone in team E, and often the FM answered the telephone and so had to be asked first. When refusing the FMs often said that they were very happy and pleased with the services, but they did not want the patients disturbed by an interview; two FMs said that they did not want the patient to be reminded of their disease; and one said that it would tire the patients to have a visitor.

Sixty-seven FMs were interviewed. The remaining 17 (20%) patients did not have a FM living with them or nearby who could be interviewed.

Table 6.4 Numbers of patients interviewed and reasons for no interview in the 2 support teams.

REASONS FOR NO INTERVIEW	NUMBER (%) OF PATIENTS Team A		Team E	
Died in less than three weeks	46	(39)	23	(35)
Too ill for interview	9*	(8)	5*	(8)
Patient refused	6	(5)	4	(6)
FM refused	1	(1)	3	(5)
General Practitioner refused	1	(1)	1	(2)
INTERVIEWED	54	(46)	30	(45)
TOTAL	117	(100)	66	(100)

* 7 patients lived for less than 28 days; 2 lived for less than 50 days, 1 patient lived longer but was very weak with a Karnofsky score (indicating mobility) of 50 at referral and 30 by the week of planned interview; 2 patients had senile dementia and 2 were severely depressed.

A further 19 patients in team A and 12 in team E were not at home for sufficient time for interview.

Interviews lasted 20 - 40 minutes; the time varied depending on the interviewee's response and the number of comments s/he wished to give. Some questions were missed, either because the respondent felt unable to assess an item, or because it was not relevant (e.g. 'family anxiety' for people without family). The item 'pain control', added later, was only included in 66 patient and 58 FM ratings.

6.2.2 Agreement and correlations between patient and team

Table 6.5 shows the agreement and correlations between the support team and patient ratings, and, to indicate the severity of each item, the mean patient ratings. Few problems were identified for three items - 'wasted time', 'practical aid' and 'communication from professionals to patient and family'.

Ratings of four items, 'practical aid', 'wasted time', 'pain control' and 'symptom control', showed high agreement (over 0.9 were equal or +1/-1), with weighted Kappas greater than 0.3) and significant although moderate correlations. For the item 'patient anxiety' agreement was slightly lower: and teams perceived a higher level of anxiety than patients. However, ratings were correlated, and for those patients who recorded the highest self-ratings, team ratings were as high or greater. The Kappa and correlation coefficient for the item 'communication of professionals to patient and family' was very low, but here 96% of patients rated this item as no problem (0 score). Again, in a few cases the teams perceived difficulties which were not identified by the patients. The item 'family anxiety' showed the poorest

agreement. There was a significant and moderate correlation coefficient for the total scores of all 7 items (rho = 0.66, $p < 0.0001$). Thus, the total team ratings reflected the total patient ratings.

6.2.3 Agreement and correlations between FMs and team

The agreement and correlations between the team and FM ratings are shown in Table 6.6.

Levels of agreement were lower than those found between the patient and team, except for two items: 'communication from professionals to patient and family' and 'family anxiety'. Where there were differences, team ratings tended to be lower (i.e. less severe) than FM ratings. Team and FM ratings were significantly correlated for all items except one -'wasted time'. The correlation coefficients were lower (0.20 - 0.66) than those found between team and patient ratings, except for 'communication between professionals and patient and family'. The total scores of seven items were correlated (rho = 0.44, $p < 0.001$).

6.2.4 Agreement and correlations between patient and FM ratings

Table 6.7 shows the agreement and correlations between the patient and FM ratings. The levels of agreement and correlations were slightly lower than those found between patient and team for three items, 'pain control', 'symptom control' and 'patient anxiety'. For other items levels of agreement were similar. Where there were differences FMs tended to report more

problems than did the patients. Patient and FM ratings were significantly correlated except for two items: 'wasted time' and 'communication between professionals and patient and family'. The total scores of seven items were correlated (rho = 0.53, $p < 0.001$).

Table 6.5 Team versus patient ratings. The proportion of ratings which were equal or within one score, the proportion where ratings were different, the weighted kappas and correlation coefficients.

	Proportion of pairs								
Item	number of pairs	Ratings equal	Ratings equal or +1 or -1	Team rating < patient ratings -1	Team rating > patient rating +1	Weighted Kappa	Spearman rho	Pearson r	Patient Mean (SD)
Pain control	66	0.59	0.97	0.03	0	0.53	0.66 #*	0.63 #*	1.09 (0.98)
Symptom control	76	0.42	0.91	0.05	0.04	0.40	0.59 #*	0.58 #*	1.29 (1.06)
Patient anxiety	76	0.31	0.87	0.03	0.11	0.28	0.45 #*	0.54 #*	0.78 (1.07)
Family anxiety	62	0.22	0.77	0.11	0.11	0.12	0.26 *	0.28 *	1.41 (1.28)
Practical aid	76	0.92	0.99	0	0.01	0.78	0.78 #*		0.20 (0.57)
Wasted time	78	0.94	0.96	0.01	0.01	0.48	0.49 #*		0.09 (0.40)
Communication of professionals to patient and family	74	0.77	0.89	0	0.11	0.08	0.18		0.07 (0.30)

* $p < 0.05$ #* $p < 0.0001$

Table 6.6 Team versus FM ratings. The proportion of ratings which were equal or within one score, the proportion where ratings were different, the weighted kappas and correlation coefficients.

	Proportion of pairs							
Item	number of pairs	Ratings equal	Ratings equal or +1 or -1	Team rating < FM ratings -1	Team rating > FM rating +1	Weighted Kappa	Spearman rho	Pearson r
Pain control	58	0.50	0.84	0.16	0	0.42	0.66 #*	0.62 #*
Symptom control	66	0.23	0.76	0.24	0	0.13	0.21 *	0.21 *
Patient anxiety	65	0.28	0.74	0.22	0.05	0.18	0.31 **	0.32 **
Family anxiety	66	0.32	0.74	0.21	0.05	0.15	0.20 $	0.25 *
Practical aid	67	0.82	0.99	0	0.01	0.51	0.42 #	
Wasted time	67	0.84	0.91	0.04	0.04	-0.06	-0.09	
Communication of professionals to patient and family	63	0.75	0.92	0.02	0.06	0.23	0.27 *	

$ $p = 0.05$ * $p < 0.05$ ** $p < 0.01$ # $p < 0.001$ #* $p < 0.0001$

Table 6.7 FM versus patients ratings. The proportion of ratings which were equal or within one score, the proportion where ratings were different, the weighted kappas and correlation coefficients.

Item	number of pairs	Proportion of pairs: Ratings equal	Ratings equal or +1 or -1	FM rating < patient ratings -1	FM rating > patient rating +1	Weighted Kappa	Spearman rho	Pearson r
Pain control	53	0.45	0.87	0.02	0.11	0.44	0.64 #*	0.62 #*
Symptom control	59	0.37	0.75	0.05	0.20	0.27	0.34 *	0.37 *
Patient anxiety	58	0.40	0.76	0	0.24	0.31	0.39 **	0.48 #*
Family anxiety	56	0.30	0.73	0.07	0.20	0.29	0.39 **	0.49 #*
Practical aid	59	0.88	1.00	0	0	0.68	0.60 #*	
Wasted time	61	0.85	0.93	0.03	0.03	-0.05	0.18	
Communication Professionals to Patient and family	54	0.83	0.98	0	0.02	-0.06	-0.07	

* p < 0.05 ** p < 0.01 # p < 0.001 #* p < 0.0001

Table 6.8 Differences between team, FM and patient ratings.

Item	Team versus patient: n	Wilcoxon Z	Team versus FM: n	Wilcoxon Z	FM versus patient: n	Wilcoxon Z
Pain control	66	-2.35 *	58	-3.57 #*	53	-2.54 *
Symptom control	76	-0.32	66	-2.84 **	59	-2.77 **
Patient anxiety	76	-4.05 #*	65	-1.11	58	-4.26 #*
Family anxiety	62	-0.14	66	-2.48 *	56	-1.76
Practical aid	76	-2.20 *	67	-0.24	59	-1.01
Wasted time	78	-0.54	67	-0.36	61	-0.89
Communication Professionals to Patient and family	74	-0.15 **	63	-1.50	54	-1.60
Total 7 items	51	-2.23 *	55	-2.71 **	46	- **

* p < 0.05 ** p < 0.01 # p < 0.001 #* p < 0.0001

6.2.5 Differences between patient, family and team assessments

The previous sections indicated area where differences between ratings occurred. The analysis tested if these differences were significant using Wilcoxon matched pairs signed ranks test. The results are shown in table 6.8. To demonstrate these differences, Fig. 6.1 plots the mean (95% confidence intervals) ratings for the four STAS items which showed near normal distributions and where most differences were found.

Team and patient differences

Teams tended to identify more problems than patients. Team ratings were significantly higher than patient ratings for three items, patient anxiety, practical aid and communications from professional to patient and family. (For the last two items the majority of patient ratings were zero). When summed, team ratings were also significantly higher than patient ratings.

However, for one item, pain control, team ratings were significantly lower than the patients.

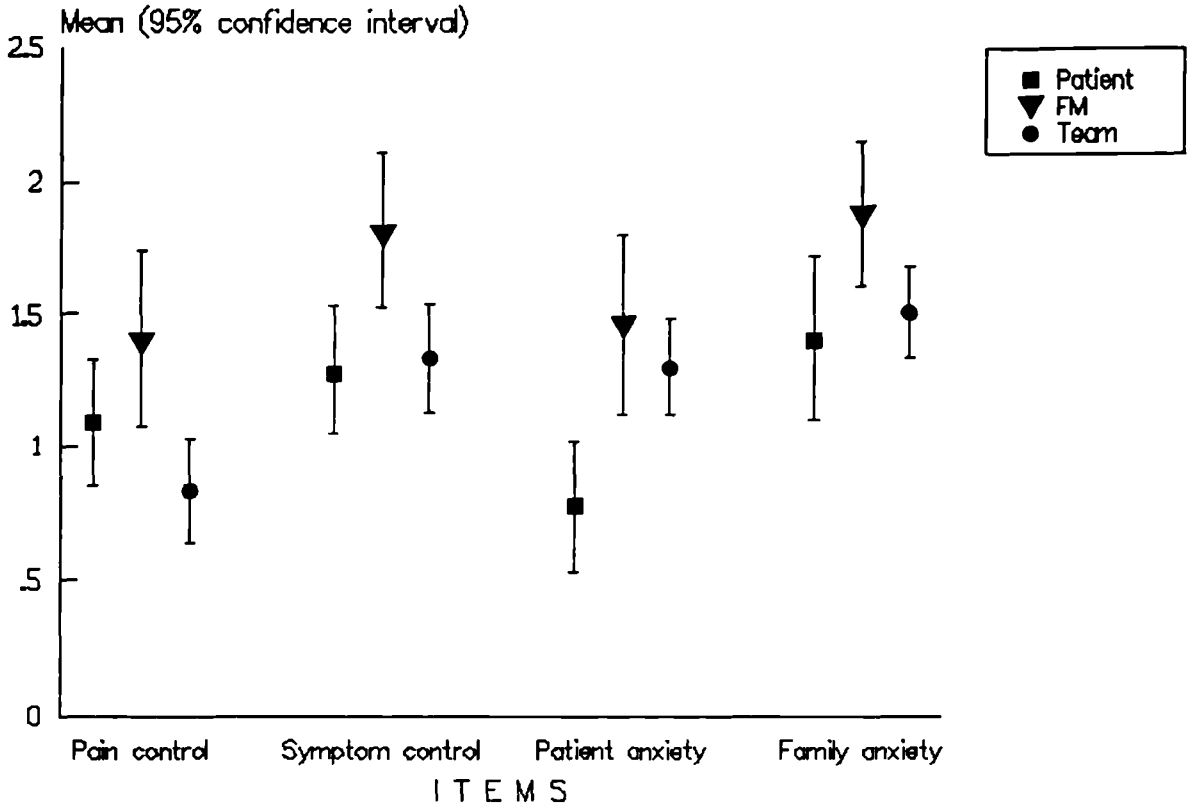
Team and FM differences

Team ratings tended to be lower than FMs' ratings. Differences were significant for three items; pain control, other symptom control and family anxiety, and for the summed score of seven items.

FM and patient differences

FMs identified more problems than patients. Often the team ratings lay between patient and FM ratings (see Fig 6.1). FM ratings were also significantly higher than patient ratings for three items: pain control, symptom control and patient anxiety, and for the summed score of seven items.

Fig. 6.1
Mean (95% CI) ratings from patient, FM and team



6.3 Results of Construct Validation using assessments according to the HRCA-QL Index

6.3.1 Data collected

Weekly assessments according to the HRCA and the STAS were collected on 179 patients in the care of team A. Of these 16 patients were assessed only once, 33 were discharged, and 3 died suddenly long before the time expected leaving 128 patients who remained in care until death. Their time in care ranged from 1 to 75 weeks; mean 9.4 weeks, median 6 weeks. Seventy-four patients spent more than four weeks in care. The item pain control was added to the STAS later, during the data collection and was recorded in 76 patients.

6.3.2 Changes in STAS and HRCA-QL ratings over time

Tables 6.9 and 6.10 show the median (interquartile range) and mean ratings for the STAS items and the HRCA QL-index, at referral and at discharge or death, for 128 patients who died in care and for the 33 who were discharged.

Patients who died in care

In the patients who died in care, between referral and death, ratings according to STAS improved, while ratings according to HRCA-QL deteriorated. Fourteen STAS items showed significant improvements (ie reductions in ratings), and three showed a trend towards improvement which did not reach significance (table 6.9). In contrast, ratings for four HRCA-QL showed significant deteriorations (reductions in score). The item 'support' showed no change.

Table 6.9 Median (inter-quartile (IQ) range) and mean ratings according to STAS and HRCA-QL for the 128 patients who remained in care until death.

ITEMS	AT REFERRAL median (IQ range)	mean	WEEK OF DEATH median (IQ range)	mean	COMPARISON OF WEEKS WILCOXON TEST Z value	P value
STAS						
Pain control	1 (0-2)	1.22	0 (0-1)	0.74	-2.88	**
Symptom control	2 (0.5-3)	1.95	2 (1-2)	1.57	-3.45	**
Patient anxiety	1.5 (1-2)	1.66	1 (0-2)	1.20	-3.44	**
Family anxiety	2 (1-3)	1.96	2 (1-2)	1.75	-1.52	NS
Patient insight	1 (0-2)	1.26	0 (0-1)	0.40	-5.99	***
Family insight	0 (0-1)	0.47	0 (0-0)	0.12	-4.24	***
Predictability	1 (1-2)	1.46	0 (0-1)	0.53	-6.63	***
Planning	1 (0-2)	1.25	0 (0-1)	0.68	-3.77	**
Practical aid	0 (0-1)	0.82	0 (0-0)	0.33	-3.53	**
Financial	0 (0-1)	0.36	0 (0-0)	0.14	-3.11	**
Wasted time	0 (0-0)	0.15	0 (0-0)	0.07	-1.17	NS
Spiritual	0 (0-0)	0.24	0 (0-0)	0.18	-0.13	NS
Communication between patient and family	2 (0-2)	1.61	0.5 (0-2)	0.92	-4.69	***
Communication between professionals	0 (0-1)	0.63	0 (0-0)	0.30	-2.62	*
Communication of professionals to patient and family	0.5 (0-2)	0.94	0 (0-0)	0.23	-5.45	***
Professional anxiety	1 (0-1)	0.69	0 (0-0)	0.35	-3.90	**
Advising professionals	1 (0-2)	1.14	0 (0-1)	0.48	-4.96	***
Total 6 STAS items	7(5.5-9.5)	7.77	4 (2-6)	4.64	-4.36	***
HRCA-QL						
Mobility	1 (1-1)	1.09	0 (0-1)	0.45	-6.87	***
Daily Living	1 (0-1)	0.98	0 (0-1)	0.32	-6.68	***
Health	1 (0-1)	0.70	0 (0-1)	0.30	-4.89	***
Support	2 (2-2)	1.75	2 (2-2)	1.74	-0.57	NS
Outlook	1 (1-1)	1.14	1 (0-1)	0.79	-4.17	***
QL Total	6 (4-7)	5.66	3 (2-5)	3.61	-7.57	***

* $p < 0.01$, ** $p < 0.005$, *** $p < 0.00005$ Wilcoxon signed ranks test, comparing ratings in weeks of referral and death. NS = not significant.

Table 6.10 Median (inter-quartile (IQ) range) and mean ratings according to STAS and HRCA-QL for the 33 discharged patients.

ITEMS	AT REFERRAL		WEEK OF DISCHARGE		COMPARISON OF WEEKS	
	median (IQ range)	mean	median (IQ range)	mean	WILCOXON TEST Z value	P value
STAS						
Pain control	1 (1-2)	1.20	0.5 (0-1)	0.78	-1.86	0.06
Symptom control	2 (1-2)	1.50	1 (1-2)	1.42	-0.06	NS
Patient anxiety	2 (1-3)	1.94	2 (1-2)	1.57	-1.82	0.07
Family anxiety	2 (2-3)	2.18	1 (0-2)	1.43	-2.45	0.01
Patient insight	1 (0-2)	1.00	0 (0-1)	0.46	-2.37	0.02
Family insight	0 (0-1)	0.52	0 (0-0)	0.09	-2.02	0.04
Predictability	1 (0-2)	1.13	0 (0-1)	0.69	-2.34	0.02
Planning	2 (1-2.5)	1.68	0 (0-2)	1.12	-1.47	NS
Practical aid	0 (0-0)	0.39	0 (0-0)	0.10	-1.78	0.07
Financial	0 (0-0)	0.21	0 (0-0)	0.19	-0.55	NS
Wasted time	0 (0-0)	0.47	0 (0-0)	0.27	-1.83	0.07
Spiritual	0 (0-0)	0.42	0 (0-0)	0.09	-1.34	NS
Communication between patient and family	1 (0-3)	1.48	0.5 (0-2)	1.40	-0.42	NS
Communication between professionals	0 (0-0.5)	0.47	0 (0-0)	0.33	-1.10	NS
Communication of professionals to patient and family	0 (0-1)	0.68	0 (0-0)	0.21	-2.52	0.01
Professional anxiety	1 (0-2)	1.25	0 (0-1)	0.63	-2.39	0.02
Advising professionals	1.5 (0-2)	1.47	0 (0-1)	0.57	-3.01	**
Total 6 STAS items	9 (6-12)	8.71	7 (3-8)	5.86	-1.75	0.08
HRCA-QL						
Mobility	1.5 (1-2)	1.47	1 (1-2)	1.41	-0.84	NS
Daily Living	1.5 (1-2)	1.37	1 (1-2)	1.14	-2.20	0.03
Health	1 (1-1)	1.00	1 (1-1)	0.97	-0.00	NS
Support	1 (1-2)	1.27	2 (1-2)	1.38	-1.34	NS
Outlook	1 (1-1)	1.00	1 (1-1)	1.10	-0.80	NS
QL Total	6 (5-8)	6.10	6 (5-8)	6.00	-0.74	NS

* $p < 0.01$, ** $p < 0.005$, Wilcoxon signed ranks test, comparing ratings in weeks of referral and discharge. NS = not significant.
Where $0.01 < p < 0.10$, actual p value is given.

To compare the scales further, ratings were considered in patients at different times before dying, irrespective of their time of referral. This demonstrates the extent which scales are affected by the process of dying. Fig. 6.2 shows the percentage of patients with a rating of 2 (best rating) for HRCA-QL items during the 11 weeks before dying. Note that the number of cases for analysis reduced in the weeks distant from death: 68 cases were available at six weeks before death, and 38 at 11 weeks before death. Again, ratings according to four HRCA-QL items - mobility, daily living, health, and outlook - deteriorated towards death. Chi-squared tests for trend were highly significant (Fig. 6.2). This was despite the fact that patients had spend different amounts of time in support team care. Deteriorations were most marked in the last 4 weeks before dying and the four items showed similar trajectories. One item, support, was different: ratings showed little change. Mean ratings showed similar trajectories.

Results were different when the percentages of patients with a rating of 0 (best rating) for STAS items during the 11 weeks before dying were considered (Figs. 6.3 and 6.4). These showed varied patterns in patients towards death and any trends were less marked. For five items - 'predictability', 'family insight', 'patient insight', 'patient anxiety' and 'communication between patient and family' - there was a trend towards improving scores towards death. For two items 'advising professionals' and 'professional anxiety' there was a trend towards deteriorating scores near death. For the remaining ten items there were no

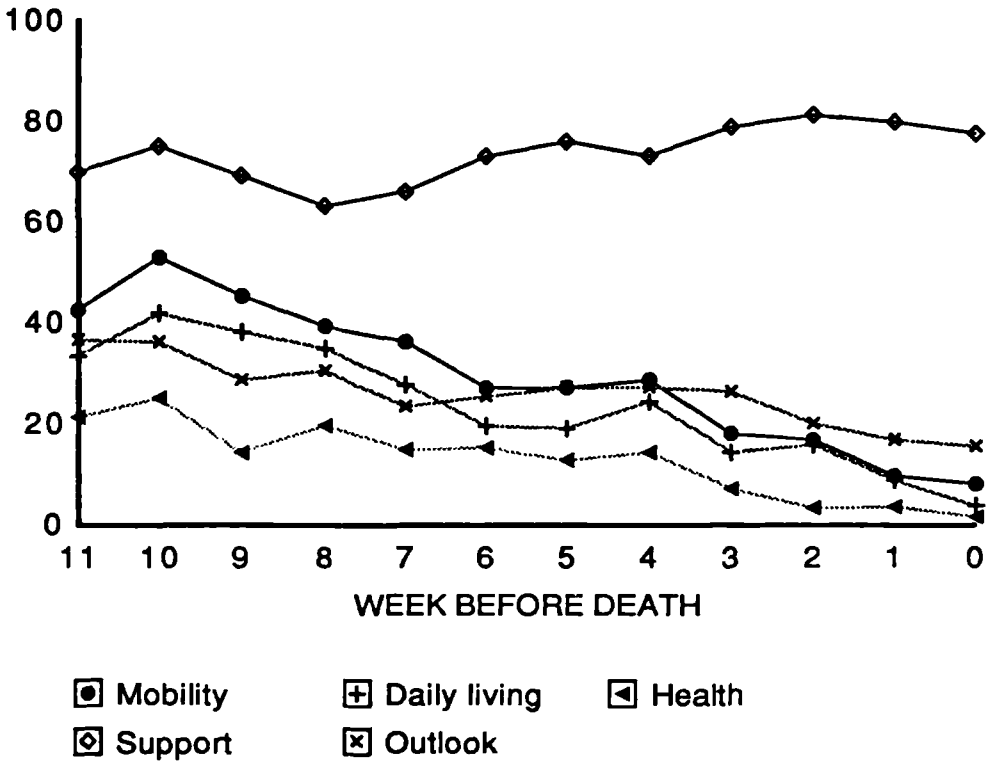
significant trends. Mean scores showed a similar pattern.

These results support the assumptions, in section 5.6.1, that STAS and HRCA-QL measure different things and would behave differently in patients as death approached. These assumptions were used as the basis for setting hypothesis to test construct validity.

Patients who were discharged

There were only 33 discharged patients. Between referral and discharge there were trends towards improvements in ratings for all STAS items, which rarely reached significance (table 6.10). For the HRCA-QL, there was a trend towards a deterioration for one item 'daily living', but no other trends. Therefore, marked deterioration in the ratings for four HRCA-QL items appeared to be confined to the effect of dying.

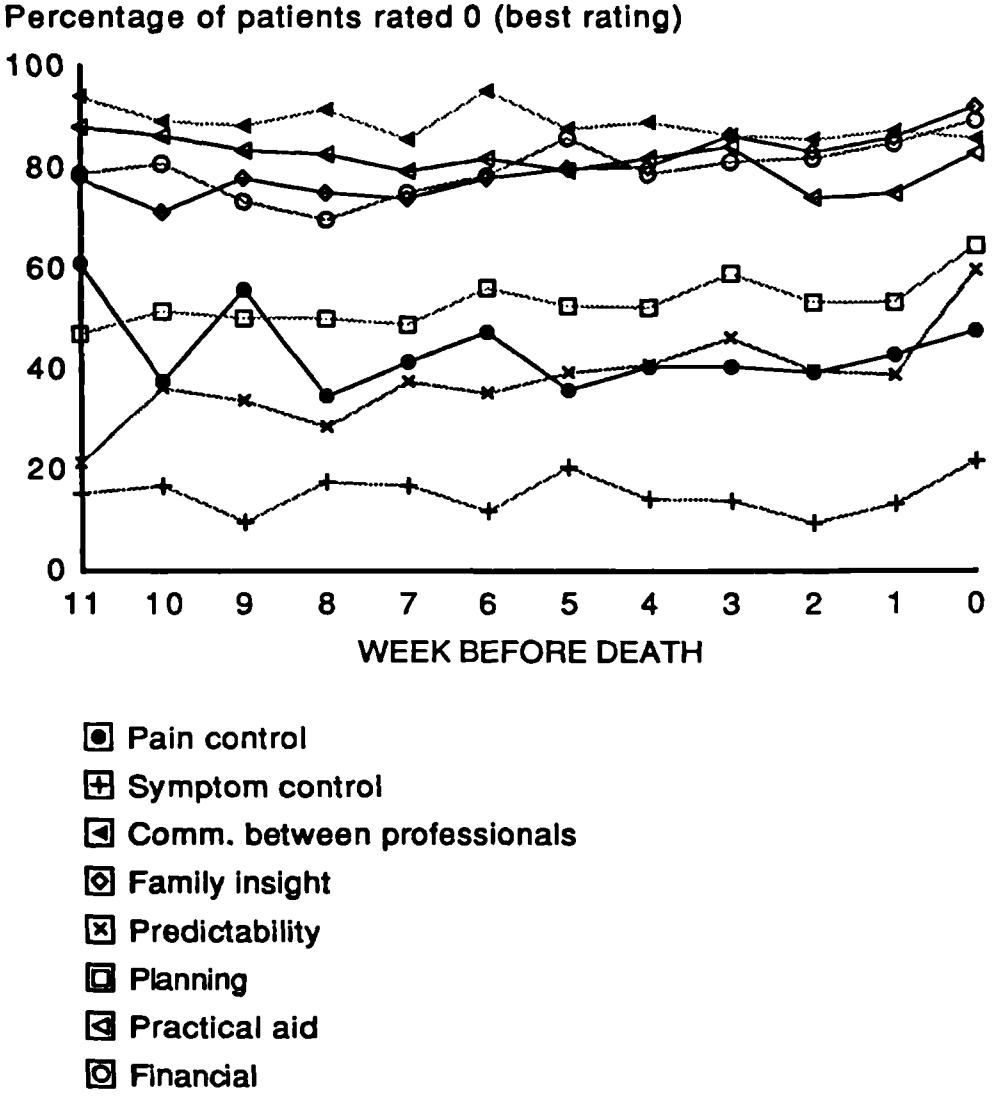
Fig. 6.2
HRCA-QL item scores in the 11 weeks before death
All patients irrespective of time of referral



Chi-squared test for trend

```
Mobility       - chi-squared = 30.50, df=1, p < 0.000001.
Daily living   - chi-squared = 29.31, df=1, p < 0.000001
Health         - chi-squared = 20.09, df=1, p < 0.000001
Outlook        - chi-squared = 14.86, df=1, p = 0.0001.
Support        - chi-squared =  2.17, df=1, p = 0.14 (NS)
```

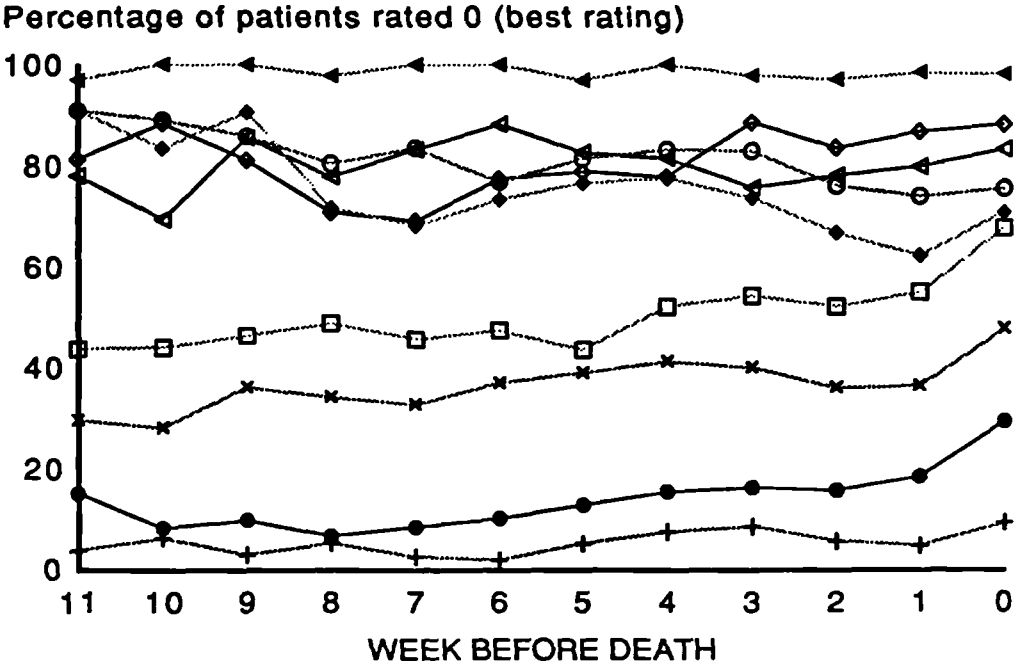
Fig. 6.3
STAS item scores in the 11 weeks before death
All patients irrespective of time of referral



Chi-squared test for trend (test results shown where p < 0.05)

Family insight - chi-squared = 8.21, df=1, p = 0.004.
Predictability - chi-squared = 18.57, df=1, p = 0.00002.

Fig. 6.4
STAS item scores in the 11 weeks before death
All patients irrespective of time of referral



- Patient anxiety
- Family anxiety
- Wasted time
- Spiritual
- Comm. between patient & family
- Patient insight
- Comm. professionals to patient
- Professional anxiety
- Advising professionals

Chi-squared test for trend (test results shown where p < 0.05)

Patient anxiety	- chi-squared = 7.90, df=1, p = 0.005.
Communication between patient and family	- chi-squared = 4.80, df=1, p = 0.03.
Patient insight	- chi-squared = 9.50, df=1, p = 0.002.
Professional anxiety	- chi-squared = 4.42, df=1, p = 0.03.
Advising professionals	- chi-squared = 12.80, df=1, p = 0.0003.

6.3.3 Correlations between STAS and HRCA-QL

The remaining analysis considers the correlations between STAS and HRCA-QL items in the 128 patients who died in care. The number of discharged patients was too small for this analysis. Table 6.11 shows the significant correlations found in:

a) all 128 patients, at referral

b) the 74 patients who were in care for more than four weeks, at referral and,

c) all 128 patients, at death.

a) Hypothesis 1 - Negative correlations between items which were similar

In patients at referral, highly significant ($p < 0.0005$) negative correlations were found between the scores of 3 STAS items ('symptom control', 'patient anxiety' and 'family anxiety') and the STAS sub-total, and 2 HRCA-QL items ('health' and 'outlook') and the HRCA-QL total (table 6.11). This supported hypothesis 1 of the strongest correlations where the indices were similar.

b) Hypothesis 3 - correlations highest in patients early in care.

The correlation coefficients were larger in the group of 74 patients who were in care for more than 4 weeks before dying. As predicted, the strongest correlations found between STAS and HRCA-QL items were in these data, between patient anxiety (STAS) and outlook (HRCA-QL), rho = -0.70, and symptom control (STAS) and health (HRCA-QL), rho = -0.64.

In patients at death, there were fewer correlations between the patient orientated STAS items and the HRCA-QL index. These findings further supported hypothesis 3. STAS items - 'pain control', 'symptom control' and 'patient anxiety' - showed significant negative correlations (rho = -0.39, -0.25, and -0.28 respectively, all $p < 0.005$) with the HRCA-QL item 'support' (the one item least likely to deteriorate at death). High ratings for the STAS item 'family anxiety', were associated low ratings for the HRCA-QL item 'outlook', but the Spearman rho was lower (rho = -0.25, $p < 0.005$). The sub-total of 6 STAS items was not significantly correlated with the total HRCA-QL score in patients at death.

Positive correlations

Weak positive correlations were found, in patients near death, between 2 STAS items: 'patient insight' and 'predictability', and 2 HRCA-QL items: 'mobility' and 'daily living' (table 6.11). Thus, the more a patient was mobile and able to care for his/her own needs, the worse was his/her insight and the greater the need to predict the course of the disease. This finding agreed with the experience of many clinicians, but were not predicted.

c) Hypothesis 2 - few correlations between HRCA-QL and STAS service orientated items

Lower and less significant negative correlations were found between the STAS service items and items in the HRCA-QL index, supporting hypothesis 2. At referral, where most correlations

were found, the items 'health' and 'outlook'(HRCA-QL) were correlated with the items 'planning', 'communication of professionals to patient and family', and 'advising professionals' (STAS) (rho ranging between -0.27 and -0.21, both $p < 0.01$). 'Communication between professionals' (STAS item) was correlated with 'health' (HRCA-QL) and 'professional anxiety' (STAS) was correlated with 'outlook' (HRCA-QL). 'Practical aid' (STAS) was also correlated with the HRCA-QL items 'mobility' and 'daily living'.

These weak associations between STAS service items and 'health' and 'outlook'(as measured by the HRCA-QL index) made sense to clinicians, who would expect a patient referred in poor health to require more services. Similarly, patients with poor mobility or unable to self care (as indicated by the HRCA-QL items 'mobility' and 'daily living') might have a higher requirement for practical aids (indicated by a high score on the STAS item 'practical aid').

Table 6.11 Spearman correlations (rho) between STAS items and the HRCA-QL index, at referral and in the week of death, for all 128 patients who died in care, and at referral in the 74 patients who remained in care for more than 4 weeks.

	AT REFERRAL IN ALL PATIENTS			AT REFERRAL IN PATIENTS WHO WERE IN CARE > 4 WEEKS			AT DEATH IN ALL PATIENTS		
STAS items	HRCA-QL items showing correlation	rho	n	HRCA-QL items showing correlation	rho	n	HRCA QL items showing correlation	rho	n
Pain control							Support	-0.39 ##	76
Other symptom control	Health	-0.49 ##	126	Health	-0.64 ##	74	Support	-0.25 #	122
	Support	-0.24 #	125	Outlook	-0.32 #	74			
	Outlook	-0.37 ##	126						
Patient anxiety	Health	-0.32 ##	124	Health	-0.41 ##	73	Support	-0.28 #	117
	Outlook	-0.60 ##	124	Outlook	-0.70 ##	73			
Family anxiety	Daily living	-0.29 #	114	Daily living	-0.32 ##	66	Outlook	-0.25 #	108
	Health	-0.41 ##	114	Health	-0.47 ##	66			
	Outlook	-0.44 ##	114	Outlook	-0.50 ##	66			
Patient insight							Mobility	0.22 **	114
							Daily living	0.24 ##	114
Family insight				Outlook	-0.29 **	66			
Predictability				Outlook	-0.32 #	74	Mobility	0.32 ##	120
							Daily living	0.24 ##	120
							Health	0.36 ##	120
Planning	Health	-0.22 **	117	Outlook	-0.40 ##	73	Daily living	0.22 **	112
	Outlook	-0.27 #	117				Health	0.27 **	112
Practical aid	Mobility	-0.27 #	124				Daily living	0.22 **	119
	Daily living	-0.25 #	124				Health	0.25 **	119
Wasted time				Health	-0.30 ##	74	Mobility	0.22 **	121
Spiritual	Mobility	0.38 #	58	Outlook	-0.51 #	37			
Communication between patient and family							Support	-0.25 ##	109
Communication between professionals	Health	-0.24 #	126	Health	-0.36 **	74			
Communication professionals to patient and family	Health	-0.28 #	122	Health	-0.40 ##	72	Daily living	0.22 **	119
	Outlook	-0.30 ##	122	Outlook	-0.36 **	72			
Professional anxiety	Outlook	-0.27 #	126	Support	-0.28 **	73			
				Outlook	-0.37 #	74			
Advising professionals	Health	-0.27 #	125						
	Outlook	-0.21 **	125						
STAS 6 item sub-total	QL Total	-0.43 ##	57	QL Total	-0.45 **	35			

** $p < 0.01$ # $p < 0.005$ ## $p < 0.0005$

6.4. Results of reliability of the STAS:

6.4.1 Assessments of simulated patients

The results of 40 paired assessments, which tested patients with widely ranging problems and severity, are shown in table 6.12. Ratings for 16 of the 17 items were equal or +1/-1 score for 0.88 or more of the cases. For these 16 items, the tests for agreement, corrected for chance agreement using Cohen's Kappa (weighted), showed levels well above the pre-set level of 0.3 (Kappa ranged 0.48-0.87) and were highly significant ($p < 0.0005$). The paired assessments were correlated, Spearman's rho ranged between 0.65 and 0.94, $p < 0.0005$. One item, 'predictability', showed lower levels of agreement and correlations, and did not reach the pre-set standards for reliability.

Where missed assessments were recorded, the pairs commonly agreed on a missed assessment.

Table 6.13 shows the results from testing for agreement between 9 raters on 5 patients. Again there was good agreement for 16 items, all except 'predictability'. Ratings for the 16 items were equal or +1/-1 score for 0.89 or more of the cases. The ratings given by the teams for some of the patients are shown in appendix J (tables J.1 to J.5). These are ratings of five of the simulated patients described appendix I. All the intraclass correlation coefficients (ICCs) showed significantly less variance between the raters assessments than between different patients, with moderate and high coefficients ranging 0.41 - 0.95.

Table 6.12 40 paired assessments. Proportion of pairs where ratings were equal, equal or +1 or -1, weighted kappas and correlations.

Correlation of total scores of 17 items, Spearman rho = 0.95 $p < 0.0005$, Pearson r = 0.95 $p < 0.000005$ (n=40)

Item	n	Ratings equal	Ratings equal or +1 or -1	Weighted Kappa	Spearman rho	MISSED ASSESSMENTS Number	Number agreed
Pain control	40	0.8	1.0	0.87 #*	0.93 #*	0	-
Symptom control	40	0.73	1.0	0.83 #*	0.93 #*	0	-
Patient anxiety	40	0.38	0.98	0.55 #*	0.79 #*	0	-
Family anxiety	29	0.45	0.97	0.59 #*	0.79 #*	11	11
Patient insight	39	0.59	0.92	0.62 #*	0.73 #*	1	1
Family insight	27	0.70	0.93	0.68 #*	0.78 #*	13	12
Predictability	39	0.34	0.74	0.25 #	0.35 *	1	1
Planning	37	0.62	0.95	0.60 #*	0.75 #*	3	3
Practical aid	35	0.63	1.0	0.71 #*	0.86 #*	5	4
Financial	33	0.70	0.97	0.73 #*	0.79 #*	7	7
Wasted time	33	0.88	0.97	0.79 #*	0.91 #*	7	3
Spiritual	24	0.83	0.92	0.81 #*	0.90 #*	16	13
Communication between patient and family	29	0.45	0.90	0.59 #*	0.81 #*	11	8
Communication between professionals	37	0.78	1.0	0.84 #*	0.94 #*	3	1
Communication from professionals to patient and family	34	0.71	0.97	0.75 #*	0.84 #*	6	1
Professional anxiety	40	0.6	0.98	0.50 #*	0.68 #*	0	-
Advising professionals	40	0.48	0.88	0.48 #*	0.65 #*	0	

* $p < 0.05$ ** $p < 0.01$ # $p < 0.005$ #* $p < 0.0005$

Table 6.13 Nine teams ratings of five patients. Proportion of ratings which were equal to the most commonly recorded ratings, or equal or +1 or -1, and intraclass correlations coefficients.

Item	Ratings equal	Ratings equal or +1 or -1	Intraclass correlation coefficient	
Pain control	0.87	1.0	0.95	#*
Symptom control	0.8	1.0	0.93	#*
Patient anxiety	0.6	0.97	0.81	#*
Family anxiety	0.69	0.97	0.87	#*
Patient insight	0.71	0.93	0.74	#*
Family insight	0.61	0.94	0.73	#*
Predictability	0.53	0.73	0.35	#
Planning	0.76	1.0	0.82	#*
Practical aid	0.75	1.0	0.84	#*
Financial	0.82	0.96	0.90	#*
Wasted time	0.95	0.98	0.66	#*
Spiritual	0.90	0.93	0.89	#*
Communication between patient and family	0.64	0.89	0.78	#*
Communication between professionals	0.8	0.98	0.87	#*
Communication from professionals to patient and family	0.75	1.0	0.86	#*
Professional anxiety	0.78	0.98	0.41	#*
Advising professionals	0.51	0.93	0.68	#*

# $p < 0.005$ #* $p < 0.0005$

6.4.2 Internal consistency

Table 6.14 shows the split half reliability Spearman Brown coefficients and Cronbach's alpha for STAS ratings at referral, at death or discharge, and on all weeks (combined) made on the the 179 patients assessed by team A. The number of cases where all 17 STAS items could be analysed was only 34 at referral and 35 at death because the items 'spiritual' and 'family insight' had frequently been missed, and the item 'pain control' was added to STAS later and so was not recorded in all cases. To analyse the homogenicity of STAS but include the majority of cases, internal consistency was also reported in shortened scales omitting these 3 items, as follows:

a) 16 STAS items (omitting 'spiritual')

b) 15 items (omitting 'spiritual' and 'pain control') and

c) 14 items (omitting 'spiritual', 'pain control' and 'family insight').

Internal consistency of STAS at referral and death

In ratings at referral and in those at death, levels of reliability according to all tests were moderately high for measure with 14-17 items, with coefficients ranging 0.68 - 0.89 for the various combinations of items. The levels are similar to those found in the development of Spitzer's QL index, described as 'high' for a 5 item measure, where Cronbach's alpha = 0.775.

Levels of reliability were similar in the full 17 items and the 16 items, and very slightly lower when 15 and 14 items were tested.

Internal consistency of STAS in all interim weeks

When ratings from all weeks in care were considered the internal consistency was slightly lower.

Internal consistency of HRCA-QL

Coefficients ranged 0.35 - 0.77 and were lower than those found for STAS and lower that those found by Spitzer in the development of the QL index (see table 6.15).

Table 6.14 Standardised item Cronbach's alpha and split-half reliability using equal length Spearman-Brown for STAS: applied to different weeks of care.

Week reliability tested and scale - items included	n	Spearman Brown	Cronbach's Alpha
At Referral			
STAS - all items	34	0.76	0.74
STAS - 16 items: except spiritual	75	0.81	0.77
STAS - 15 items: except spiritual and pain control	127	0.75	0.73
STAS - 14 items: except spiritual pain control and family insight	129	0.72	0.71
At death or discharge			
STAS - all items	33	0.87	0.82
STAS - 16 items : except spiritual	73	0.81	0.82
STAS - 15 items : except spiritual and pain control	122	0.71	0.76
STAS - 14 items : except spiritual pain control and family insight	122	0.71	0.75
All interim weeks: note - more than one assessment per patient			
STAS - all items	310	0.51	0.57
STAS - 16 items : except spiritual	557	0.70	0.66
STAS - 15 items : except spiritual and pain control	938	0.67	0.70
STAS - 14 items : except spiritual pain control and family insight	950	0.64	0.68

Table 6.15 Standardised item Cronbach's alpha and split-half reliability using equal length Spearman-Brown, for the HRCA-QL index: applied to different weeks of care.

Week reliability tested	n	Spearman Brown	Cronbach's Alpha
At Referral	186	0.36	0.62
At death/discharge	181	0.35	0.67
All interim weeks: note - more than one assessment per patient	1134	0.47	0.71

6.5 Results: characteristics of patients and FMs referred to the five teams during the audit.

6.5.1 Demographic and personal characteristics of patients

During the study 581 patients were referred to the teams. Of these, 311 (54%) were male and 270 (46%) female, mean age was 66 years (median = 67 years) range 19 - 92 years (table 6.16). Most patients were of British origin, 430 (81%), 44 (8%) were Irish, 12 (2%) other European, and 43 (7%) other nationalities (missing 52). Of those who declared religious views, 215 (53%) were Church of England, 109 (27%) Roman Catholic, 19 (5%) Jewish, 40 (10%) other religion and 23 (6%) agnostic or atheist (missing = 175, 30% of all patients).

Tables 6.16 and 6.17 and Fig. 6.5 show these characteristics for the different teams. Teams A and E were referred most patients (192 and 126 respectively), but in all teams data on 80 or more patients was collected. The ages of patients referred to teams B and C were significantly lower than those referred to the other teams (table 6.16). There were no significant differences between the teams in the proportions of men and women referred. Fig. 6.5 shows that teams C and E (New Town and Outer London teams) saw mostly British patients (96 and 94% respectively) whereas the inner London teams had 24 - 28% of patients who were of other national origins.

Table 6.16 Age and sex of patients referred to five teams

Team	AGE			SEX n (%)		Total
	mean (95% confidence interval)	median	range	Men	Women	referred
A	67.6 (66.1-69.0)	67	32 - 92	111 (58)	81 (48)	192
B	63.0 (60.0-66.0)	64	19 - 89	44 (55)	36 (45)	80
C	62.2 (59.3-65.2)	63	35 - 86	39 (49)	41 (51)	80
D	66.8 (64.5-69.1)	68	32 - 88	54 (52)	49 (48)	103
E	66.0 (64.0-67.9)	67	37 - 90	63 (50)	63 (50)	126
All cases	65.8 (64.8-66.7)	67	19 - 92	311 (54)	270 (47)	581

One way analysis of variance of age:
F ratio = 4.26, df = 4 (between groups), 561 (within groups), p = 0.002.

Chi-squared of sex distribution = 2.90, df = 4, p = not significant.

Table 6.17 Religions of patients referred to the five teams

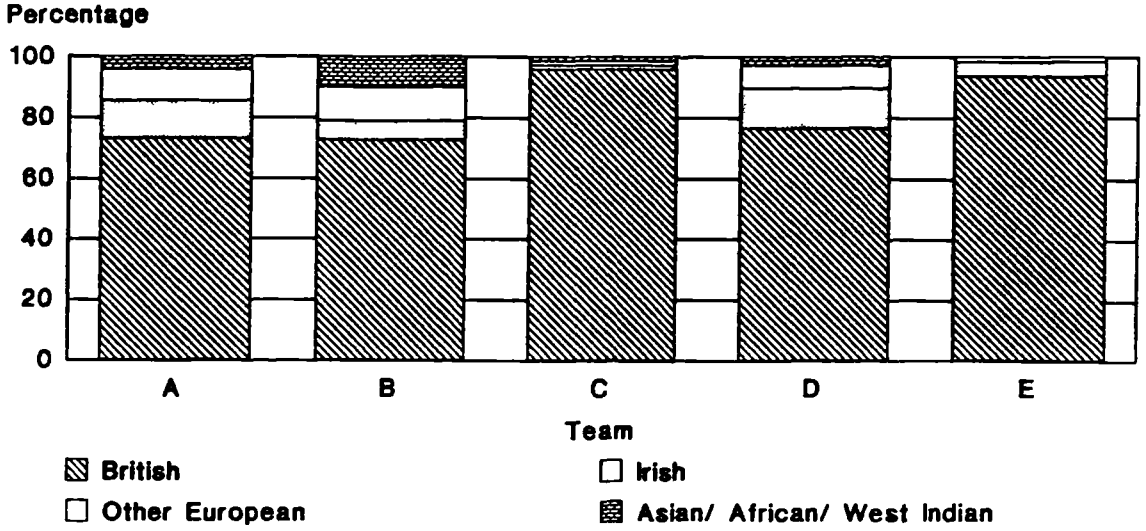
Team	n	Church of England	Roman Catholic	Jewish	Other Religion	Agnostic/ atheist	Not recorded	Total referred
A	149	65 (44)	43 (29)	14 (9)	15 (10)	12 (8)	43	192
B	62	37 (60)	17 (27)	1 (2)	7 (11)	-	18	80
C	57	41 (72)	9 (16)	1 (2)	4 (7)	2 (4)	23	80
D	39	15 (40)	20 (51)	-	2 (5)	2 (5)	64	103
E	99	57 (58)	20 (20)	3 (3)	12 (12)	7 (7)	27	126
All cases	406	215 (53)	109 (27)	19 (5)	40 (10)	23 (6)	175	581

Chi-squared = 34.08, df = 12, p = 0.0007 (of Church of England, Roman Catholic, other religion (including Jewish), or agnostic/atheist)

Fig. 6.5

Nationalities of patients referred to the five teams

Chi-squared = 35.76, df = 4, p < 0.000001 (missing = 52)



Whether religious faith was recorded or not varied from team to team (table 6.17). Team D recorded the faith in only 38% of patients, whereas other teams recorded faith in 71-79%. Teams C, B and E had the largest proportion of patients whose faith was Church of England (58-72%): the Roman Catholic faith was also common in teams D, A and B (27-51%). These figures reflected the national origins of patients, although conclusions cannot be drawn for team D owing to missing data. (National origin was recorded in a higher proportion, 66%, for team D.)

Patient's accommodation

Although social class was not recorded, the type of accommodation provides information on social circumstances. The tenancy of patients' accommodation was: 43% council, 40% owner-occupied, 9% private rented, 2% hostel, 1% warden aided and 5% other (including nursing homes). Fig. 6.6 shows that owner occupation was common for teams E (79%) and C (60%) (Outer London and New Town) but more rare in the Inner London teams, especially team A (12%). Team D had the largest proportion of private rented accommodation (29%). One hundred and twenty one patients (27%) lived in accommodation where the outside access was by stairs with no lift (table 6.18). This was a particular feature of inner London teams (A,B,D). The relationship of accommodation type and access is shown in table 6.19: private rented and council accommodation had the highest proportions (55% and 38%) where access was by stairs only.

Fig. 6.6

Tenancy of patients referred to the five teams

Chi-squared = 175.1, df = 12, p < 0.000001 (missing = 125)

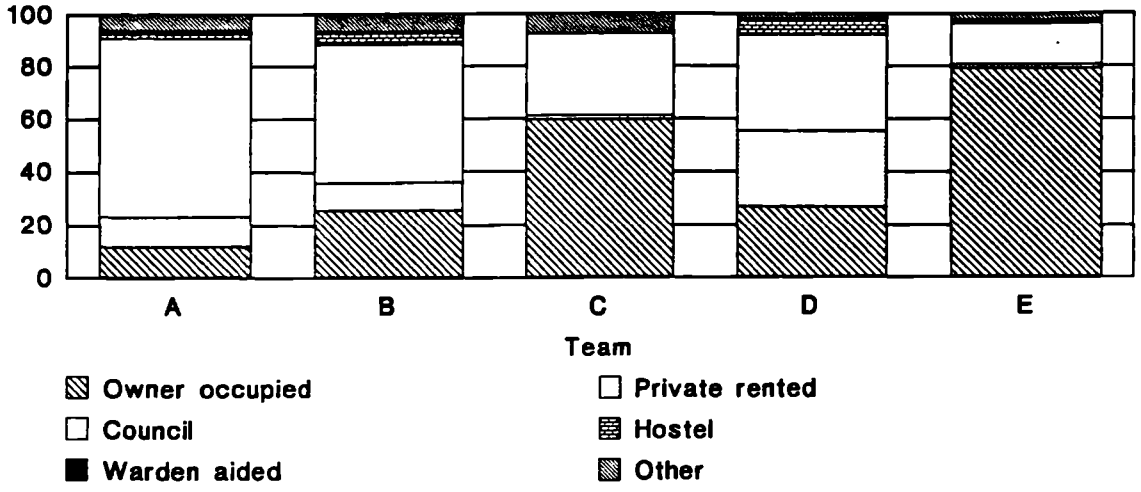


Table 6.18 Access to the patients' homes for the five teams

		ACCESS n (%)					
Team	n	Ground floor	By lift or stairs	By stairs only	Not recorded	Total referred	Proportion recorded
A	167	48 (29)	46 (28)	73 (44)	25	192	78%
B	54	25 (46)	11 (20)	18 (33)	26	80	78%
C	61	54 (89)	1 (2)	6 (10)	19	80	71%
D	38	22 (58)	5 (13)	11 (29)	65	103	38%
E	121	108 (89)	-	13 (11)	5	126	79%
All cases	441	257 (58)	63 (14)	121 (27)	140	581	70%

Chi-squared = 137.9, df=8, p < 0.00005

Table 6.19 Access to the accommodation for patients with different tenancies

		ACCESS n (%)		
Tenancy	n	Ground floor	By lift or stairs	By stairs only
Owner occupied	175	155 (89)	1 (1)	19 (11)
Private rented	38	11 (29)	6 (16)	21 (55)
Council	181	67 (37)	46 (25)	68 (38)
Other	28	17 (61)	6 (21)	5 (18)
Total	422	250 (59)	59 (14)	113 (27)

missing = 159: note in some cases access was known but tenancy was unknown.

Chi squared = 123, df = 6, p < 0.00001

Patient's status

The current status of the patients was: 337 (59%) married, 119 (21%) widowed, 64 (11%) single (always), 41 (7%) divorced or separated and 6 (1%) changing status during the care (e.g. patients who got married) (14 missing). Table 6.20 shows how status varied between teams: teams A, C and D had the highest percentage of widowed patients (24-25%) (despite team C having younger patients than A and D) and A,B and D had many single patients (15-16%).

Forty-eight percent of patients lived with one other person. Twenty-three percent lived alone, this was lowest in team E (9%) and highest in teams A (30%) and D (32%) (Fig. 6.7).

Table 6.20 Status of patients referred to five teams

Team	STATUS n (%)					
	Married/ partnered	Widowed	Divorced/ separated	Single	Changing	Total
A	100 (52)	46 (24)	13 (7)	30 (16)	3 (2)	192
B	50 (63)	9 (11)	8 (10)	13 (16)	/	80
C	49 (65)	18 (24)	5 (7)	3 (4)	/	75
D	48 (51)	23 (25)	8 (9)	14 (15)	1 (1)	94
E	90 (71)	23 (18)	7 (6)	4 (3)	2 (2)	126
All cases	337 (60)	119 (21)	41 (7)	64 (11)	6 (1)	567*

* missing = 14

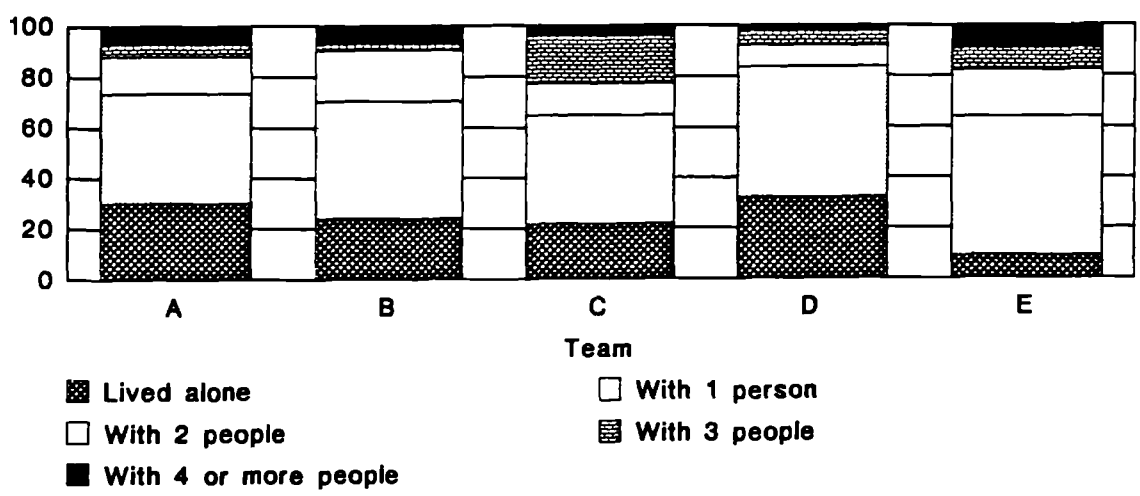
Chi-squared = 30.7, df = 12, p = 0.002 (omitting 'changing' from the analysis)

Fig. 6.7

Number of people the patients lived with

Chi-squared = 34.17, df = 12, p = 0.0006 (missing = 37)

chi-square of alone, 1, 2, or 3+ persons



6.5.2 The nearest family member or carer

A nearest family member or carer (FM) could be identified for 546 patients (96%, missing = 12). Twenty-three patients (4%) had no FM: this was highest for teams A (6%) and B (8%). In contrast, only 1 patient referred to team E had no carer (Fig. 6.8). The most common FM was a wife (36% of patients), followed by a husband, 22%, and a daughter, 13%. Other carers were: sister 3.7%, brother 1.2%, friend 4.4%, other 7.7%.

To examine whether the FMs would be able to provide care for the patient, the employment of FMs and their Karnofsky Performance Status was recorded at first assessment. Thirty-eight percent of FMs had full-time paid employment outside the home and 8% had part-time employment, however this information was missed in 101 patients. Fig. 6.9 shows that team E had the highest proportion of FMs with full or part-time employment (47%). Of patients referred to each team, between 42.3% (team E) and 56.5% (team A) had FMs who were retired or had no paid employment and could be at home with them during the day.

A few FM were disabled and could not have cared for the patient: some even needed the patient to care for them. Forty (8.2%) carers had Karnofsky ratings of 80 - 60, indicating they were usually unable to carry out normal activities, and 7 (1.4%) carers were severely disabled (Karnofsky ratings 30 - 50) (missing = 35).

Fig. 6.8

Main carers of patients

Chi-squared = 44.89, df = 16, p = 0.0001 (missing = 12)

chi-squared combined: son & daughter; sibling, friend, other

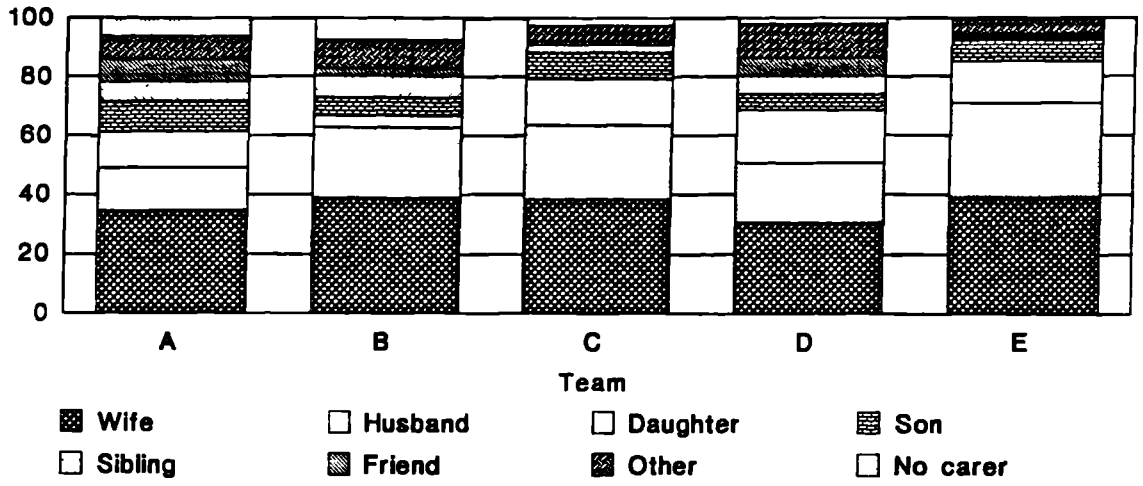
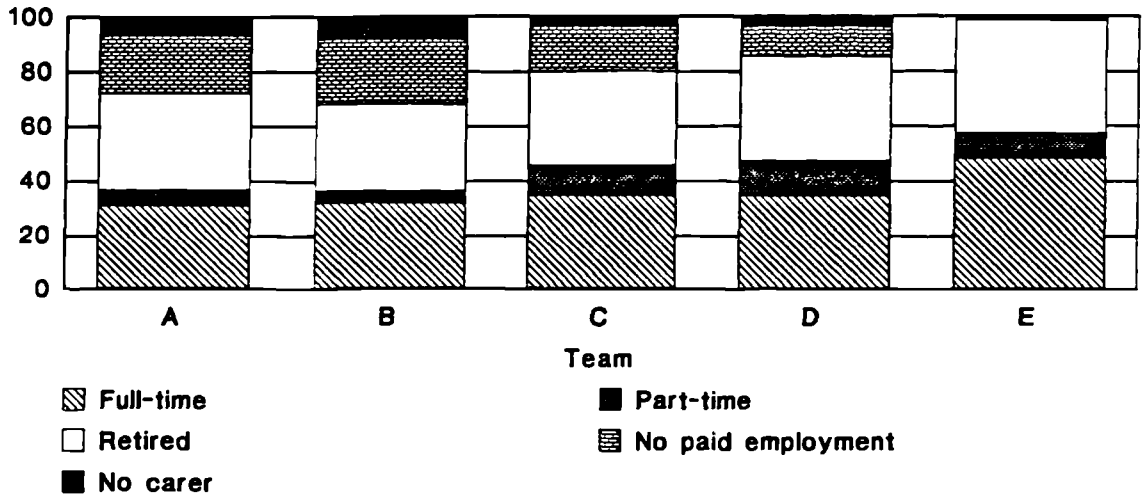


Fig. 6.9

Family member's (or main carer's) employment

Chi-squared = 46.3, df=16, p < 0.0001 (missing = 101)



6.5.3 Clinical characteristics of patients

All patients except two had cancer (one patient had motor neurone disease and one had AIDS). The most common primary diagnoses were cancers of gastrointestinal tract (28%), lung and bronchus (23%), genitourinary tract (18%) and breast (10%) (table 6.21). The percentage of different cancers varied between teams, and to examine this in more detail the cancers referred were compared with local mortality from cancer. Table 6.22 shows the number of deaths from cancer among local residents during the study period for each team. The referral rates per 100 resident cancer deaths were remarkably similar, 33 for teams A - D and lower, 23 for team E (table 6.23). However, unlike teams A - D, team E did not serve the whole of their health district, because another (older) team served a part of it. Mortality rates for the locality served by team E were not available.

The number of expected referrals, for different primary cancers in each team, was calculated from the number of resident deaths during the study period (OPCS data) multiplied by the referral rate for all cancers to that team. This was compared with the observed number of referrals. Table 6.23 shows the ratio of observed / expected referrals for different primary cancers. Team B had far fewer lung cancer patients than would be expected (observed/expected (O/E) = 0.39). It transpired that in the district of team B there was a separate services of home support for all patients with continuing lung problems, including those with lung cancer. Many lung cancer patients were referred to this service.

In three teams there were more referrals than expected of cancers of the ear, nose and throat (O/E ranged 2.21 - 4.15). Cancer of the lymphatic system were referred less than would be expected in four teams.

The primary cancer or its metastasis was the main cause of symptoms: 265 (47%) and 276 (49%) of patients, respectively. Other diseases, not related to the cancer, were the main cause of symptoms for few patients (22 patients - 4%) (missing = 18).

Table 6.21 Cancers of patients referred to the five teams.

Team	n	PRIMARY CANCER n (%) Lung	Gastro-intestinal	Genito-urinary	Ear, nose & throat	Breast	Lymphatic	Other cancers	Primary unknown
A	192	55 (29)	54 (28)	28 (15)	14 (7)	15 (8)	8 (4)	6 (3)	12 (6)
B	78	10 (13)	24 (31)	20 (26)	4 (5)	6 (8)	3 (4)	4 (5)	7 (9)
C	77	14 (18)	13 (17)	19 (25)	3 (4)	10 (13)	4 (5)	8 (10)	6 (8)
D	100*	29 (29)	26 (26)	16 (16)	2 (2)	10 (10)	6 (6)	7 (7)	3 (3)
E	126+	23 (18)	41 (33)	19 (15)	1 (1)	16 (13)	3 (2)	12 (10)	10 (8)
All cases	573	131 (23)	158 (28)	102 (18)	24 (4)	57 (10)	24 (4)	37 (7)	38 (7)

missing = 8

* Includes one patient with HIV/AIDS

\+ Includes one patient with motor neurone disease

Table 6.22 Numbers of residents who died of cancer in each team's health district, during the study period. Numbers are estimated from OPCS data for 1 year, (1988)

Team	Period of data collection	NUMBER OF DEATHS FROM CANCERS DURING STUDY PERIOD Lung	Gastro-intestinal	Genito-urinary	Ear, nose & throat	Breast	Lymphatic	Other cancers	All cancers
A	17 months	170.0	162.9	93.5	9.9	59.5	51.0	58.1	613.4
B	6 months	77.0	51.5	37.5	5.5	23.5	15.5	25.5	236.5
C	6 months	55.5	73.5	33.0	2.5	26.0	17.0	25.0	234.0
D	8 months	97.3	78.7	47.3	7.3	24.7	12.7	34.0	303.3
E	8 months	124.7	152.7	90.7	9.3	55.3	32.0	73.3	544.7

Table 6.23 Observed / expected referrals for each cancer type based on each team's referral rate. Expected referral rate calculated from number of OPCS deaths in study period x individual team's referral rate for all cancers.

Team	Referral rate per 100 resident cancer deaths (all types)	OBSERVED / EXPECTED FOR EACH CANCER Lung	Gastro-intestinal	Genito-urinary	Ear, nose & throat	Breast	Lymphatic	Other cancers
A	33.30	1.03	1.06	0.96	4.51	0.88	0.50	0.86
B	32.98	0.39	1.41	1.62	2.21	0.77	0.59	1.28
C	32.91	0.77	0.54	1.75	3.65	1.17	0.72	1.61
D	32.97	0.90	1.00	1.03	0.83	1.23	1.44	0.94
E	23.13	0.80	1.16	0.91	0.46	1.25	0.41	1.24

6.5.4 Source of referral

Patients were referred by: general practitioners (GPs) (25%), radiotherapists (18%), surgeons (19%), physicians (15%), medical oncologists (3%), and others, mostly ward nurses, (20%). Teams B and E accepted referrals only from consultants or GPs and therefore had no referrals in the 'other' category, whereas most (59%) referrals to team C were from nurses (Fig. 6.10). The community based teams received most referrals from general practitioners (team E, 56% and team A, 24%). Only 2 patients were referred by GPs to team B.

The most common first two reasons for referral were: symptom control (1st or 2nd reason in 284 (50%) patients) and home support (1st or 2nd reason in 159 (28%)), followed by patient support or relief of anxiety (1st or 2nd reason in 137 (24%)), and family support or relief of anxiety (1st or 2nd reason in 133 (23%).

Time from cancer diagnosed to referral

Nineteen percent patients were referred within one month of their diagnosis of cancer, only eight percent were greater than five years from diagnosis. In all teams there was a mix of patients at all times after diagnosis (Fig. 6.11), although the community based teams were referred the lowest percentage who were within one month of diagnosis (18% for team A, 10% team E).

Fig. 6.10

Referrers to the five teams

Chi-squared = 301.1, df=20, p < 0.00005 (missing = 12)

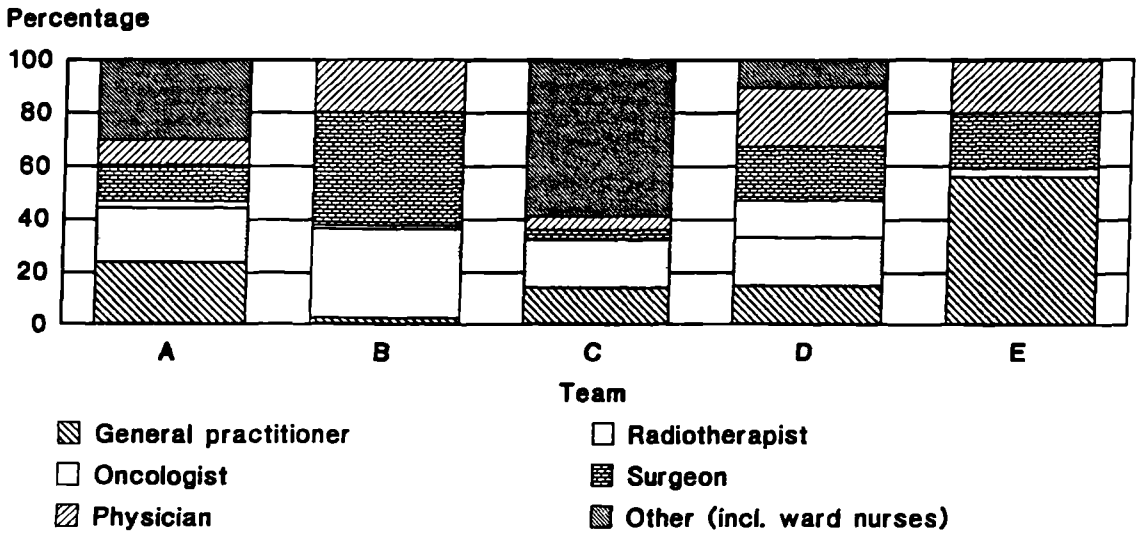
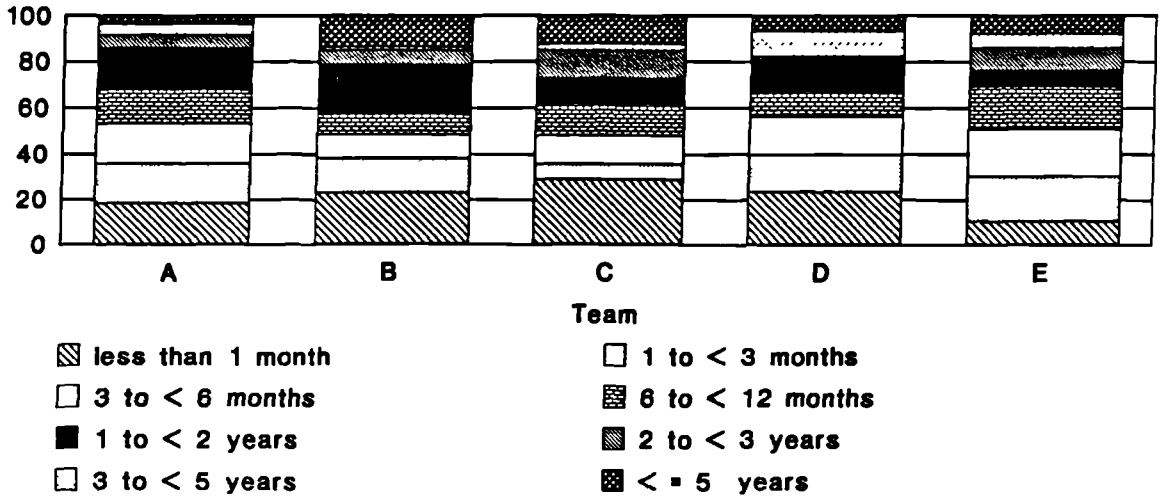


Fig. 6.11

Time from cancer diagnosed to referral to team

Chi-squared = 59.3, df=28, p < 0.0005 (missing = 38)



6.5.5 Place of care

Two hundred and sixty patients (53%) were at home when referred, 172 (36%) were in hospital, 50 patients (10%) were transferring between hospital and home and two patients were transferring between hospice and home (n = 484, as this was only recorded for patients who had STAS ratings subsequently recorded).

Of the 473 patients for whom place of death was recorded (in a high proportion of the discharged patients this was not known), 202 patients (43%) died at home, 191 (40%) died in hospital, 72 (15%) died in a hospice and 8 (2%) died in nursing homes and elsewhere.

6.6 Audit results: STAS ratings during care by five teams

6.6.1 Patients included in audit

STAS ratings were commenced for 487 patients (see table 6.24). Team D had staff shortages, and for six months was reduced to only one nurse rather than two, shortly after they began data collection. Team D wished to remain in the study and was keen to collect the demographic and clinical data on patients, but wanted to stop collecting the audit data until staffing levels returned to normal. This was agreed. In a few other cases patients referred for care died before they could be assessed. For 53 (10.9%) patients, STAS ratings were recorded only at referral, and the patients then died or were discharged before a second assessment was made. This was most common in the hospital based teams (B,C and D). Two or more STAS ratings were recorded in the remaining 434 (89.1%) patients: 98 were subsequently discharged and not re-admitted during the study, two died suddenly of diseases other than their cancer, and 334 were in team care at death. Table 6.24 shows these figures for the different teams.

Table 6.24 Number of patients in each team who commenced audit, died or were discharged after one rating or who had 2 or more ratings completed before death or discharge.

		number of patients (% of those for whom STAS ratings were commenced)				
Team	Total referred	STAS ratings commenced	Discharged or died after referral rating	2 or more ratings completed		
				total	died	discharged
A	192	191	17 (8.9)	174 (91.1)	131 (68.6)	43 (22.5)
B	80	80	13 (16.3)	67 (83.8)	38 (47.5)	28 (35.0)*
C	80	65	10 (15.4)	55 (84.6)	49 (75.4)	5 (7.7)*
D	103	27 **	4 (14.8)	23 (85.2)	16 (59.3)	7 (25.9)
E	126	124	9 (7.3)	115 (92.7)	100 (80.6)	15 (12.1)
All cases	581	487	53 (10.9)	434 (89.1)	334 (68.6)	98 (20.1)

* A further one patient in the care of team B and one in the care of team C died suddenly, not from their cancer.

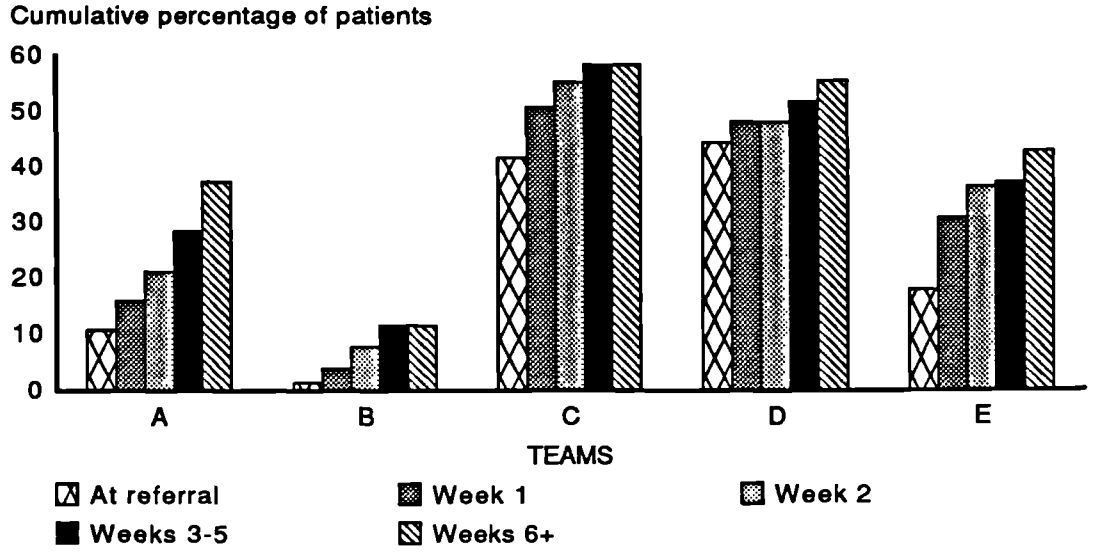
** Number low because team stopped audit for six months owing to staff shortages.

6.6.2 Full assessments of all 17 STAS items

Full assessments, where ratings for all 17 STAS items were recorded, were found for only 82 (16.8%) patients at referral. A further 58 (11.9%) patients were fully assessed by the end of the second week of care, and 46 (9.4%) were fully assessed after this. However, 301 (61.8%) patients never had a full assessment recorded before death or discharge.

There were significant differences between teams. Fig. 6.12 shows the proportion of patients with full assessments at different stages during care. Team B recorded a full assessment for only one patient at referral, and increased this to nine patients only slowly. Teams C and D recorded full assessments in over 40% of patients at referral, and were able to improve this to over 55%.

Fig. 6.12
Cumulative percentage of patients in each team who had all 17 STAS items recorded at different stages during care



Chi-squared comparing the number of full assessments first completed, at referral, weeks 1-2, weeks 3+ or never = 92.4, df=12, $p < 0.00005$.

6.6.3 Late and missed STAS assessments

The failure to record a full assessment was often due to ratings for the item 'spiritual' being missed. This item was missed throughout care in 49.5% of patients and was assessed late (missed at first contact but then assessed later during care) in a further 22.4%. Four other items - 'financial', 'family insight', 'family anxiety' and 'communication between patient and family' - were quite commonly assessed late (20.3-24.4% of patients) and were missed in 9.9 - 16.6%. The remaining items were occasionally assessed late (3.9 - 17.1%) but were missed in less than 9.5% of patients (table 6.25).

There were significant differences between the teams in the pattern of missed and late assessments for six items (tables 6.26 to 6.31). Team B recorded the highest proportion of late and missed assessments for the items 'spiritual'(table 6.26) and 'financial' (table 6.27). In contrast, team C only missed assessments for the item 'spiritual' in 15.4% of patients, considerably lower than any other team, and team D recorded no missed assessments for the item 'financial'. However, team B had the lowest proportion of late and missed assessments for the item 'planning' (table 6.28).

Team B and D, both hospital based, recorded more late and missed assessments than other teams for those items concerned with the family - 'family anxiety' (table 6.29), 'family insight' (table 3.30) and 'communication between patient and family'(table 3.31). Perhaps their hospital base made it more difficult for

them to meet family members. However, team C, also hospital based, did not share their difficulties.

Table 6.25 STAS ratings which were assessed late (missed at first contact but then assessed later during care) or were missed throughout care, in the 487 patients included in the audit.

Item	Assessed late n	(%)	Missed throughout care n	(%)
Pain control	26	(5.3)	2	(0.4)
Symptom control	21	(4.3)	3	(0.6)
Patient anxiety	37	(7.6)	14	(2.9)
Family anxiety	99	(20.3)	50	(10.3)
Patient insight	69	(14.2)	46	(9.5)
Family insight	107	(22.0)	48	(9.9)
Predictability	44	(9.0)	6	(1.2)
Planning	84	(17.3)	34	(7.0)
Practical aid	43	(8.8)	16	(3.3)
Financial	119	(24.4)	81	(16.6)
Wasted time	36	(7.4)	15	(3.1)
Spiritual	109	(22.4)	241	(49.5)
Communication between patient and family	115	(23.6)	58	(11.9)
Communication between professionals	23	(4.7)	7	(1.4)
Communication from professionals to patient and family	43	(8.8)	12	(2.5)
Professional anxiety	19	(3.9)	2	(0.4)
Advising professionals	25	(5.1)	6	(1.2)

Table 6.26 STAS item 'spiritual'. Late and missed assessments for the five teams.

Team	n	Assessed at referral n (%)	Assessed late n (%)	Missed throughout care n (%)
A	191	41 (21.5)	41 (21.5)	109 (57.1)
B	80	7 (8.8)	12 (15.0)	61 (76.3)
C	65	46 (70.8)	9 (13.8)	10 (15.4)
D	27	8 (29.6)	10 (37.0)	9 (33.3)
E	124	35 (28.2)	37 (29.8)	52 (41.9)

Chi-squared = 97.45, DF = 8, $p < 0.00005$

Table 6.27 STAS item 'financial'. Late and missed assessments for the five teams.

Team	n	Assessed at referral n (%)	Assessed late n (%)	Missed throughout care n (%)
A	191	121 (63.4)	45 (23.6)	25 (13.1)
B	80	28 (35.0)	28 (35.0)	24 (30.0)
C	65	54 (83.1)	6 (9.2)	5 (7.7)
D	27	20 (74.1)	7 (25.9)	0
E	124	64 (51.6)	33 (26.6)	27 (21.8)

Chi-squared = 46.76, DF = 8, $p < 0.00005$

Table 6.28 STAS item 'planning'. Late and missed assessments for the five teams.

Team	n	Assessed at referral n (%)	Assessed late n (%)	Missed throughout care n (%)
A	191	137 (72.8)	32 (16.8)	20 (10.5)
B	80	76 (95.0)	3 (3.8)	1 (1.3)
C	65	56 (86.2)	8 (12.3)	1 (1.5)
D	27	19 (70.4)	8 (29.6)	0
E	124	79 (63.7)	33 (26.6)	12 (9.7)

Chi-squared = 38.67, DF = 8, $p < 0.00005$

Table 6.29 STAS item 'family anxiety'. Late and missed assessments for the five teams.

Team	n	Assessed at referral n (%)	Assessed late n (%)	Missed throughout care n (%)
A	191	128 (67.0)	43 (22.5)	20 (10.5)
B	80	35 (43.8)	30 (37.5)	15 (18.8)
C	65	53 (81.5)	5 (7.7)	7 (10.8)
D	27	18 (66.7)	7 (25.9)	2 (7.4)
E	124	104 (83.9)	14 (11.3)	6 (4.8)

Chi-squared = 44.85, DF = 8, $p < 0.00005$

Table 6.30 STAS item 'family insight'. Late and missed assessments for the five teams.

Team	n	Assessed at referral n (%)	Assessed late n (%)	Missed throughout care n (%)
A	191	123 (64.4)	48 (25.1)	20 (10.5)
B	80	38 (47.5)	28 (35.0)	14 (17.5)
C	65	54 (83.1)	5 (7.1)	6 (9.2)
D	27	18 (66.7)	7 (25.9)	2 (7.4)
E	124	99 (79.8)	19 (15.3)	6 (4.8)

Chi-squared = 33.96, DF = 8, $p < 0.00005$

Table 6.31 STAS item 'communication between patient and family'. Late and missed assessments for the five teams.

Team	n	Assessed at referral n (%)	Assessed late n (%)	Missed throughout care n (%)
A	191	125 (65.4)	46 (24.1)	20 (10.5)
B	80	31 (38.8)	30 (37.5)	19 (23.8)
C	65	48 (73.8)	9 (13.8)	8 (12.3)
D	27	16 (59.3)	8 (29.6)	3 (11.1)
E	124	94 (75.8)	22 (17.7)	8 (6.5)

Chi-squared = 35.98, DF = 8, $p < 0.00005$

6.6.4 Severity of the 17 STAS items during care

The following sections describes the severity of STAS ratings, first for the 334 patients who were in care at their death, and then second for the 98 patients who were discharged. Missed assessments were excluded from the analysis. To calculate the score in weeks prior to a late assessment the score first recorded for that item was used. The data from all teams is considered together.

The 334 patients who died in care

The 334 patients spent a mean of 7.8 weeks in care, median 5 weeks (inter-quartile range 2-10 weeks). Figs. 6.13 and 6.14 show the percentages of patients with scores of 0 (no problems) through to 4 (most severe), for these patients at referral, in their second week of care and at death. Items are listed in order of severity at referral.

At referral

At referral, high proportions (22-33%) of patients had severe problems (rated 3 or 4) for four items, 'family anxiety', 'symptom control', 'patient anxiety' and 'communication between patient and family'. For another four items - 'planning', 'patient insight', 'pain control', and 'predictability'- between 17% and 18% of patients had severe problems (rated 3 or 4). For the remaining nine items - seven concerned with the services, plus 'spiritual' and 'family insight' - there were usually mild problems or none and less than 10% were rated 3 or 4.

Second week of care (week 2)

By week 2, for all items, fewer patients had severe ratings and more were rated zero (no problems). Compared to ratings at referral, differences were significant for 15 items, all except 'financial' and 'spiritual' (Wilcoxon Z ranged -2.11 to -7.95, table 6.32). The four items 'family anxiety', 'symptom control', 'patient anxiety' and 'communication between patient and family' remained relatively severe: 9-21% were rated 3 or 4. For other items, 11% or less were rated 3 or 4, and 62-97% were rated 0 or 1 (nil or mild problems).

At death

At death, three items - 'family anxiety', 'symptom control' and 'patient anxiety' - continued to be the most severe. The proportion of patients with severe ratings (score 3 or 4) increased, compared to week 2, to 29%, 25% and 15%, respectively. The percentage of patients with severe ratings for the item 'practical aid' also increased to 4% at death, compared to only 1% in week 2 (Fig. 6.14)

Ratings for other items were similar to, or slightly lower than, ratings in week 2. Ratings at death were lower than ratings at referral for all items (Wilcoxon Z ranged -2.16, $p = 0.03$, for 'family anxiety', to $Z = -9.91$, $p < 0.00005$ for 'predictability'), see table 6.32.

Fig. 6.13
Ratings for patients who died in care, at referral & week 2.
N = 334

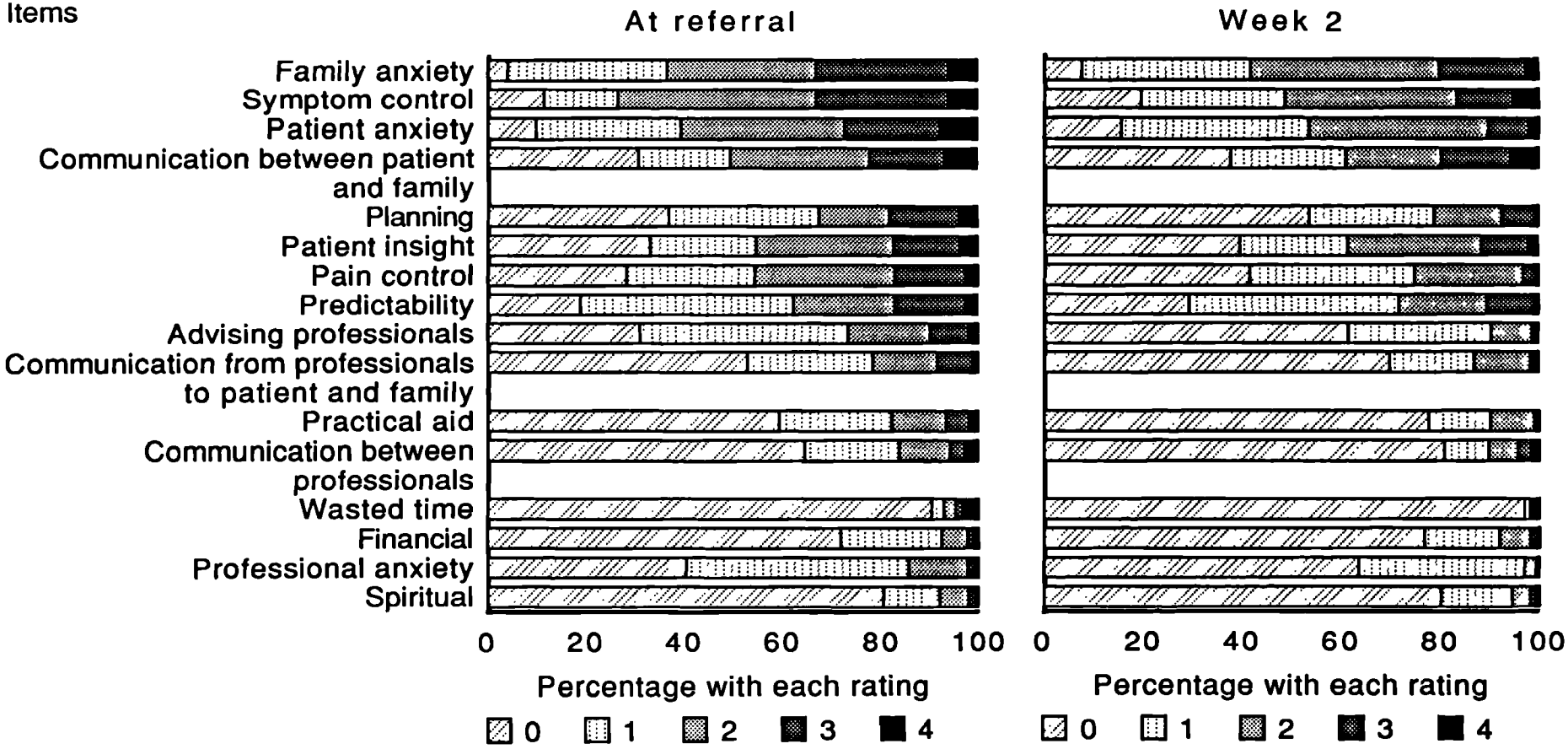


Table 6.32 Wilcoxon matched-pairs signed-ranks test for referral versus week 2 ratings and for referral versus death ratings. The 334 patients who died in care.

	Wilcoxon matched-pairs signed-ranks test					
	referral v week 2			referral v death		
Item	n pairs	Z	p value	n pairs	Z	p value
Pain control	211	-5.94	p < 0.00005	241	-5.51	p < 0.00005
Symptom control	287	-5.83	p < 0.00005	322	-5.34	p < 0.00005
Patient anxiety	279	-6.27	p < 0.00005	308	-7.06	p < 0.00005
Family anxiety	264	-3.42	p = 0.0006	294	-2.16	p = 0.03
Patient insight	269	-2.24	p = 0.03	288	-8.23	p < 0.00005
Family insight	260	-2.11	p = 0.03	291	-7.61	p < 0.00005
Predictability	288	-4.11	p < 0.00005	322	-9.91	p < 0.00005
Planning	263	-5.18	p < 0.00005	304	-8.11	p < 0.00005
Practical aid	276	-3.93	p = 0.0001	316	-5.59	p < 0.00005
Financial	242	-0.85	NS	276	-5.01	p < 0.00005
Wasted time	278	-2.50	p = 0.01	315	-3.81	p = 0.0001
Spiritual	146	-1.19	NS	162	-2.68	p = 0.007
Communication between patient and family	249	-3.85	p = 0.0001	277	-7.30	p < 0.00005
Communication between professionals	287	-3.73	p = 0.0002	322	-4.68	p < 0.00005
Communication from professionals to patient and family	280	-5.14	p < 0.00005	315	-8.11	p < 0.00005
Professional anxiety	288	-6.99	p < 0.00005	325	-5.73	p < 0.00005
Advising professionals	285	-7.95	p < 0.00005	319	-7.90	p < 0.00005

The 98 patients who were discharged

Patients who were discharged spent a similar amount of time in care to those who had died, mean = 9.2 weeks (median = 4 weeks, inter-quartile range = 2-10 weeks). Figs. 6.15 and 6.16 show the percentages of patients with scores of 0 (no problems) through to 4 (most severe), for patients at referral, in week 2 and at discharge.

Ratings at referral were of similar severity to those in the 334 patients who died in care. Ratings had improved by week 2, again in a similar pattern to those in the group of 334 patients. Differences between referral and week 2 were significant for 12 out of 17 items, but note that there was a much smaller number of patients in this analysis (table 6.33). Unlike the changes between week 2 and death, where ratings increased for some items, in the 98 discharged patients ratings reduced between week 2 and discharge. The percentages of patients with severe (3 or 4) ratings for the items 'family anxiety', 'symptom control', 'patient anxiety' and 'communication between patient and family' were 16, 14, 13, and 13, respectively. Differences between referral and discharge were significant for 14 out to 17 items, all except 'financial', 'spiritual' and 'communication between patient and family'.

Fig. 6.15
Ratings for patients who were discharged, at referral & week 2. N = 98

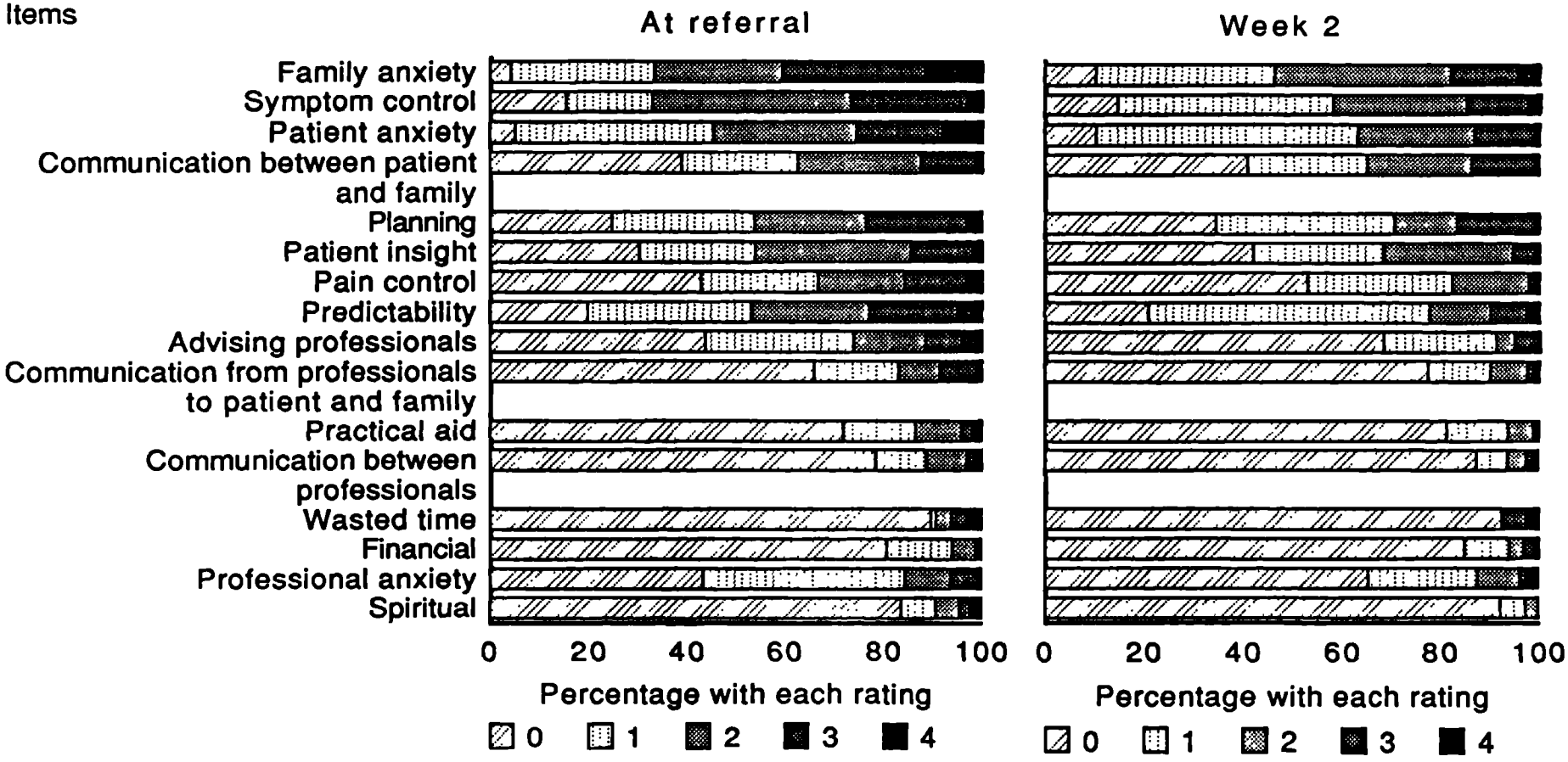


Fig. 6.16
Ratings for patients who were discharged, at discharge.
N = 98

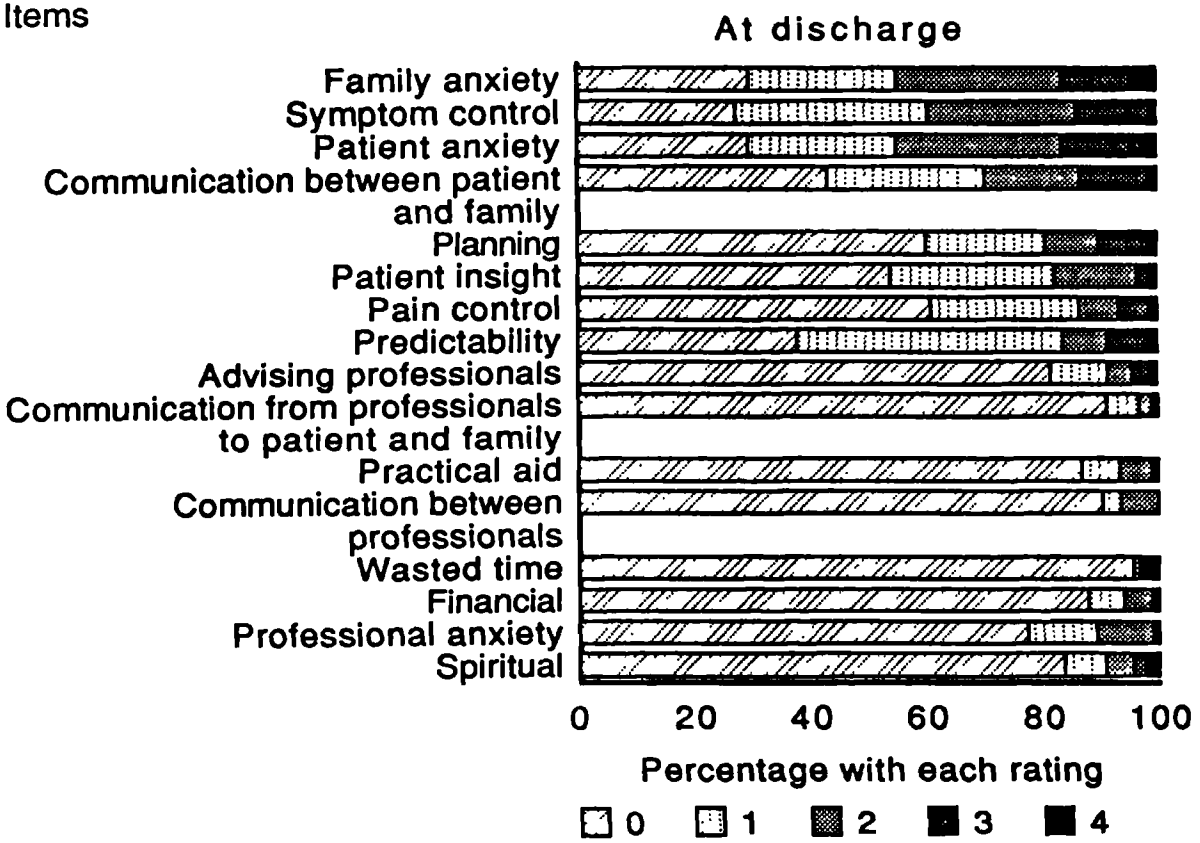


Table 6.33 Wilcoxon matched-pairs signed-ranks test for referral versus week 2 ratings and for referral versus discharge ratings. The 98 patients who were discharged.

	Wilcoxon matched-pairs signed-ranks test					
	referral v week 2			referral v discharge		
Item	n pairs	Z	p value	n pairs	Z	p value
Pain control	50	-2.98	p = 0.003	57	-3.14	p = 0.002
Symptom control	81	-3.02	p = 0.003	93	-3.62	p = 0.0003
Patient anxiety	76	-2.89	p = 0.004	92	-3.12	p = 0.002
Family anxiety	57	-3.14	p = 0.002	65	-4.52	p < 0.00005
Patient insight	74	-2.95	p = 0.003	84	-4.83	p < 0.00005
Family insight	61	-2.31	p = 0.02	69	-2.53	p = 0.01
Predictability	80	-2.99	p = 0.003	91	-5.01	p < 0.00005
Planning	77	-2.86	p = 0.004	87	-4.63	p < 0.00005
Practical aid	80	-2.42	p = 0.02	90	-2.68	p = 0.007
Financial	64	-0.32	NS	78	-1.36	NS
Wasted time	81	-0.30	NS	92	-2.37	p = 0.02
Spiritual	33	-1.34	NS	37	-1.60	NS
Communication between patient and family	59	-0.44	NS	66	-1.42	NS
Communication between professionals	80	-1.26	NS	92	-2.03	p = 0.04
Communication from professionals to patient and family	78	-2.87	p = 0.004	89	-4.43	p < 0.00005
Professional anxiety	81	-2.18	p = 0.03	92	-3.73	p = 0.0002
Advising professionals	79	-3.32	p = 0.0009	91	-4.67	p < 0.00005

NS = not significant

6.6.5 Changing symptoms during care in the 334 patients who died in care

The ratings of the item 'symptom control' and the record of a main symptom each week allows analysis of the changing main symptoms during care. Pain control was rated as a separate item, so ratings for this can be compared with other items. The analysis considers the 334 patients who died in care, the number of discharged patients with individual symptoms was not large enough for this analysis.

Fig. 6.17 shows the eight symptoms (other than pain) most commonly recorded as the main symptom at referral and at death. The most frequent main symptoms were weakness (recorded in 17.1% at referral and 16.7% at death) and dyspnoea (14.0% at referral and 15.5% at death). Between referral and death, vomiting, nausea and constipation were recorded less frequently as main symptoms, and the number of patients with no symptoms increased. However, confusion became more frequent, and depression and anorexia remained largely unchanged.

The ratings for three common main symptoms, dyspnoea, weakness and nausea and vomiting (combined) are shown in Figs. 6.18 to 6.20. Fig. 6.21 shows the ratings for pain control. Ratings for symptom control and pain control were near normally distributed (see Figs. 6.13 and 6.14). Therefore, to demonstrate changes in score during care, mean (95% confidence intervals) ratings were plotted for patients with these main symptoms at referral, week 2, death - 2 (two weeks before death) and death.

T-test was used to test for differences between the ratings in different weeks (pooled variance method).

Teams apparently failed to alleviate both dyspnoea and weakness, for there was no significant difference between ratings at referral and week 2, death-2 or death (T ranged 0.64 to -1.68, p ranged 0.5 to 0.1). Ratings for nausea and vomiting (combined) were significantly lower in the weeks of death-2 and death compared to referral (Fig. 6.20).

Fig. 6.21 shows how the ratings for the item 'pain control' were very different from these three symptoms. Ratings had improved markedly by week 2, compared to referral, and this was maintained until death.

Fig. 6.17
Eight most commom main symptoms at referral and death (excluding pain)

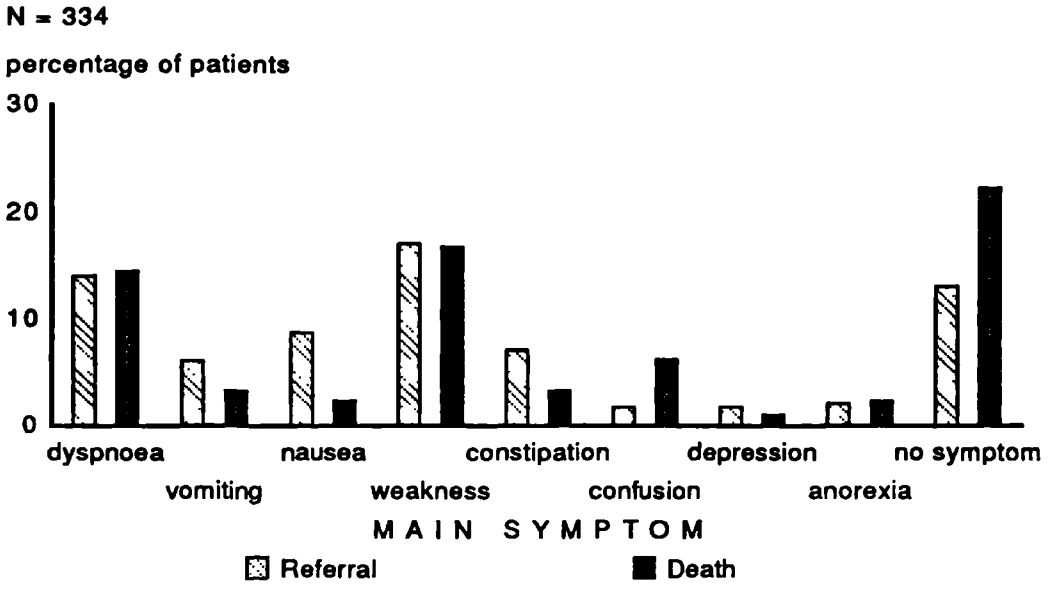


Fig. 6.18
Dyspnoea as the main symptom
Mean (95% Confidence Interval) symptom control rating

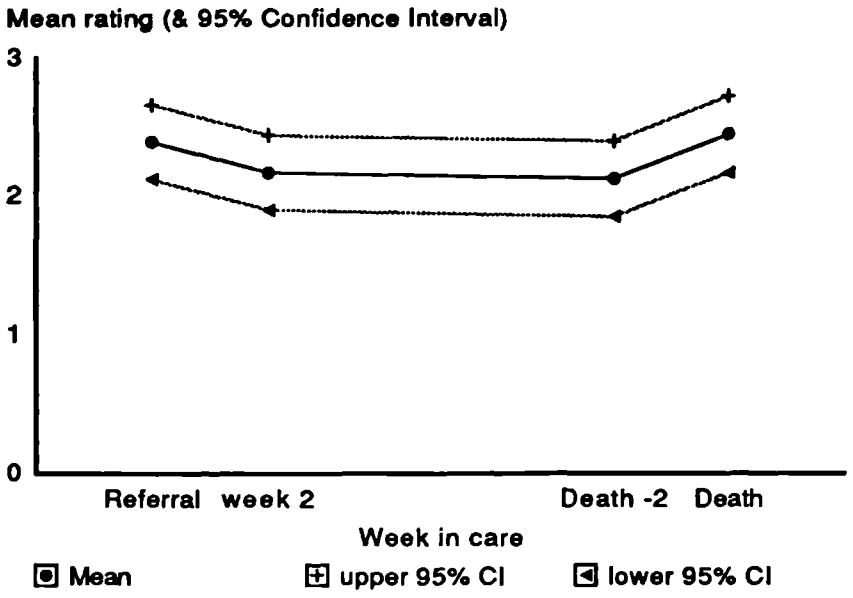


Fig 6.19
Weakness as the main symptom
Mean (95% Confidence Interval) ratings for symptom control

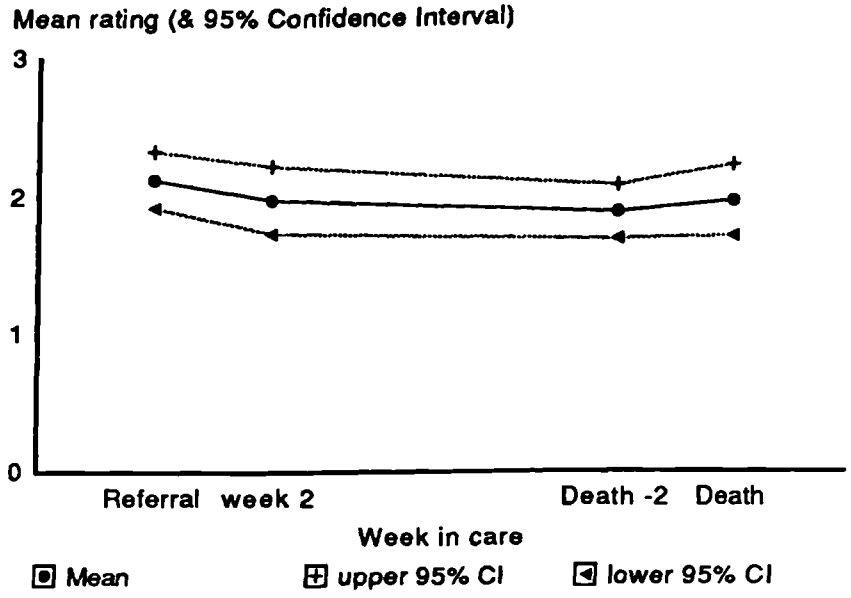


Fig. 6.20
Nausea or vomiting as the main symptom
Mean (95% Confidence Interval) ratings for symptom control

Referral versus death-2, T=-2.54, p=0.01
Referral versus death, T=-3.61, p=0.001

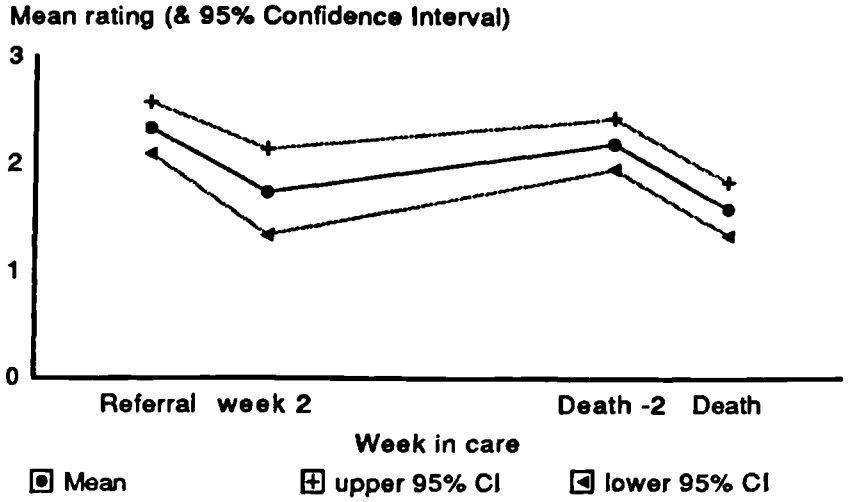


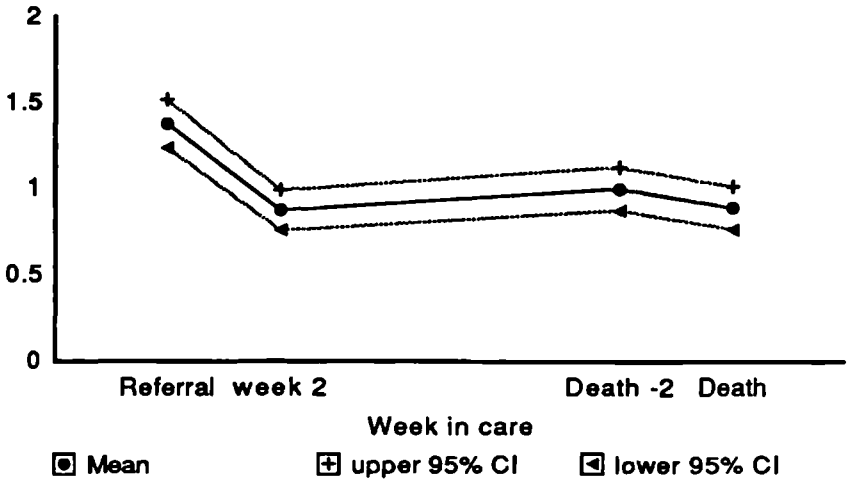
Fig. 6.21

Mean (95% Confidence Interval) ratings for pain control

Referral versus week 2, T=-3.31, p=002

Referral versus death-2, T=-4.64, p=0005

Referral versus death, T=-3.54, p=0.001



6.6.6 Properties of a total score of STAS items

Trajectories of patients' total STAS scores during care

Teams found it useful to calculate a total score by summing all STAS items. They used this to provide a quick assessment of the severity of a case. Because the items 'spiritual' and 'financial' were frequently missed or assessed late, it was agreed to calculate a total score by summing 15 items, omitting these two. The maximum possible total score was therefore 60.

Fig. 6.22 shows the trajectory of one patient during care: the total STAS ratings are shown against weeks in care. Changes in score can be linked to events, such as chemotherapy treatment or hospitalisation. This patient's history is given below the figure.

Changes in total score during care

Total scores, summing 15 items, could be calculated for up to 197 (59%) of patients who died in care. Total scores were normally distributed. Table 6.34 shows the mean (95% confidence interval) median, and range of total scores in patients at referral, week 2 and at death. Compared with scores at referral, total scores were significantly lower in week 2 (Wilcoxon matched-pairs signed-ranks test, $Z = -8.04$, $p < 0.00005$) and at death (Wilcoxon $Z = -9.04$, $p < 0.00005$). Patients varied in the extent of improvement, and some did not improve during care. Between referral and death, 82% of patients showed an improvement in total score, 16% a deterioration, and 2% did not change. In the week of death, 10 out of 172 patients (6%) had total scores of 20

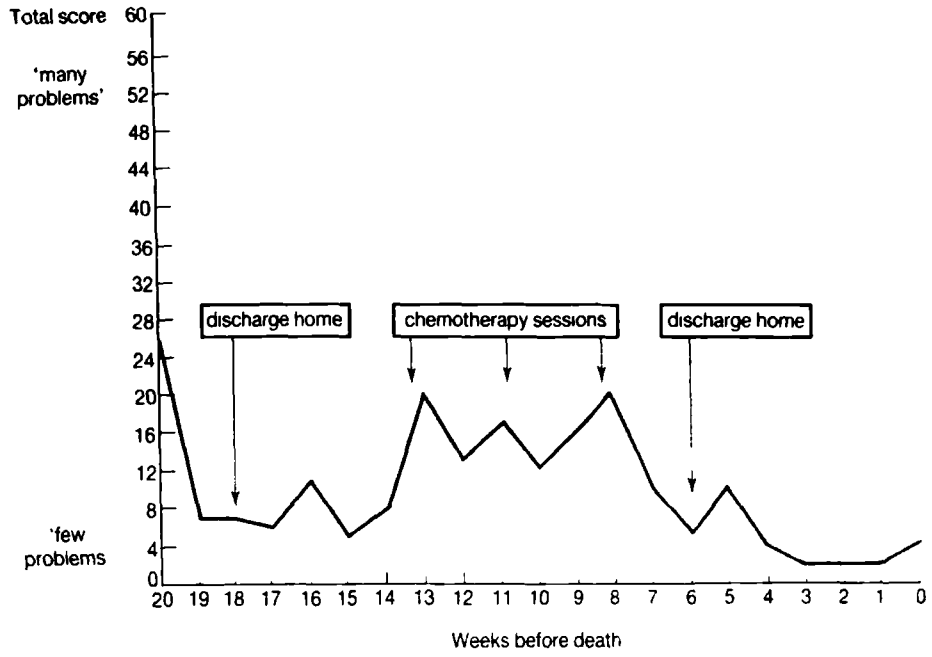
or above, which the teams considered to be clinically severe. The corresponding figure for the week of referral was 33% (65 out of 197 patients).

Properties of a total score

Teams were asked if they could weight the severity of STAS items to assist the calculation of a total score. However, they were unable to agree on weights, or even an order STAS items with the most important first.

Table 6.35 shows the correlation coefficients between the total STAS score and individual STAS items in patients at referral and death. Items are presented in order of highest correlation coefficients at referral. At referral, the items representing the anxiety of the patient and family, and communication, showed the strongest correlations with the total score (Spearman rho ranges 0.55-0.61). For five items, 'pain control', 'symptom control', and three service items correlations were weak (Spearman rho ranges 0.39-0.15) At death, the pattern changed. The items 'patient anxiety', 'family anxiety' were even more strongly correlated with the total score (Spearman rho = 0.73 and 0.75, respectively), but, unlike at referral, the items 'pain control' and symptom control' were moderately correlated with the total score (Spearman rho = 0.56 and 0.54 respectively).

Fig. 6.22
STAS total scores for one patient from referral to death.



Patient history
This was a 62 year old lady with a squamous cell carcinoma of the lung, who had recently begun a course of Iphosphamide chemotherapy. On referral to the team her main problems were symptom control, she had pain, but was vomiting when given opioids. She and her husband were very anxious, but had full insight and few problems with service co-ordination. The total score at referral was 25. When her pain and vomiting were controlled using subcutaneous morphine and anti-emetics, and her anxiety and that of her husband diminished, her total score fell to seven and she was discharged home. At home she was put on oral medication, but then was readmitted to hospital for chemotherapy, during which her total scores rose due to her, and her husband's, anxiety prior to treatment. She also developed symptoms of depression. Subsequently, she was discharged home, her problems were alleviated and remained low throughout the few weeks until her death at home.

Table 6.34 Total score of 15 STAS items (all except 'financial' and 'spiritual') at referral, week 2, and at death.

	TOTAL SCORE OF 15 STAS ITEMS					
Week	n	mean	(95% Confidence Interval)	median	minimum	maximum
At referral	197	16.5	(15.5-17.5)	16	1	39
Week 2	168	12.1	(11.2-13.1)	11	0	32
Death	172	9.4	(8.4-10.3)	9	0	34

Table 6.35 Correlations between STAS total score of 15 items with individual STAS items in patients at referral and death. Items are listed in order of size of correlation at referral.

Item	REFERRAL			DEATH			Order of correlations at death (highest first)
	n	Spearman rho	p	n	Spearman rho	p	
Communication from professionals to patient and family	197	0.61	0.0005	172	0.51	0.0005	8
Family anxiety	197	0.60	0.0005	172	0.73	0.0005	2
Patient anxiety	197	0.59	0.0005	172	0.75	0.0005	1
Communication between professionals	197	0.55	0.0005	172	0.48	0.0005	9
Predictability	197	0.55	0.0005	172	0.54	0.0005	4
Patient insight	197	0.51	0.0005	172	0.43	0.0005	12
Planning	197	0.50	0.0005	172	0.47	0.0005	10
Professional anxiety	197	0.49	0.0005	172	0.51	0.0005	7
Advising professionals	197	0.48	0.0005	172	0.47	0.0005	11
Family insight	197	0.48	0.0005	172	0.29	0.0005	15
Communication between patient and family	197	0.46	0.0005	172	0.51	0.0005	6
Spiritual	121	0.43	0.0005	101	0.31	0.001	13
Symptom control	197	0.39	0.0005	172	0.54	0.0005	5
Practical aid	197	0.31	0.0005	172	0.29	0.0005	14
Pain control	197	0.27	0.0005	172	0.56	0.0005	3
Wasted time	197	0.18	0.006	172	0.21	0.003	17
Financial	180	0.15	0.02	158	0.21	0.004	16

6.6.7 Internal consistency

Table 6.37 shows the results of the internal consistency analysis for the 487 patients who had STAS ratings recorded. The analysis considers ratings at referral, and at death or discharge, for all items, and to exclude items where missed ratings were common, 15 items (except 'spiritual' and 'pain control') and 14 items (also excluding 'financial'). Family insight was included in this analysis, because unlike in team A, enough recordings were available.

Levels of internal consistency were similar to those found when only one team had been considered. Thus the use of STAS more widely in five teams had not affected its homogenicity.

Table 6.37 Standardised item Cronbach's alpha and split-half reliability using equal length Spearman-Brown for STAS: applied to different weeks of care.

Week reliability tested and scale - items included	n	Spearman Brown	Cronbach's Alpha
At Referral			
STAS - all items	144	0.68	0.74
STAS - 15 items: except spiritual and pain control	314	0.68	0.73
STAS - 14 items: except spiritual pain control and financial	349	0.65	0.74
At death or discharge			
STAS - all items	120	0.74	0.80
STAS - 15 items : except spiritual and pain control	279	0.69	0.77
STAS - 14 items : except spiritual pain control and financial	309	0.71	0.78

7. DISCUSSION

7.1 The Support Team Assessment Schedule (STAS): content

The first objective of this study was to develop items which would be suitable as outcome measures for palliative care. Items should reflect the work and goals of support teams. Previously, measures of palliative care usually focused on parts of care, such as pain or symptom control or emotional distress (see Parkes 1985, Kane *et al* 1984). In STAS broader measures of physical, emotional, social and service problems were developed, to assess both the patient and their family member or friend. This reflected the wider goals of support teams, including their role in co-ordinating and advising other services.

The patient-orientated STAS items are similar to those included in other instruments which assess cancer and terminally ill patients (e.g. the Cancer Inventory of Problem Situations, Schag *et al* 1983, and an Initial Assessment of Suffering in Terminal Illness, MacAdam and Smith 1987); but the STAS is different in that it considers the patient and family as the unit of care, and so includes items concerned with the family. This is an essential component of support team care and palliative care (National Association of Health Authorities 1987, Saunders 1978). Unlike Wallston *et al*'s (1988) measure of the quality of death, STAS attempted to reflect the extent which each item was a problem to an individual patient and their family, taking their wishes into account.

7.1.1 Limitations of the STAS items

STAS includes 17 items across a wide range of palliative care, but detailed information on each item, for example, the type of pain or the severity of other individual symptoms, is not included. This would have been too time consuming to collect. Some clinicians wish to separately measure symptoms such as dyspnoea, weakness, nausea, vomiting, pressure sores, anorexia and constipation. The definition of the STAS item 'symptom control' could be adapted to measure individual symptoms. A first draft of definitions for individual symptoms is being tested by home care teams in Belfast and Dublin.

7.1.2 Psychological and social aspects

The psychological and social aspects of STAS could be expanded in a similar way, to include more information. In STAS, depression was recorded when this was considered to be a patient's main symptom, and was the main symptom in 1.7% of patients at referral and 1.0% at death. However, depression has been found in 21% or more cancer patients. Moderate or severe depression was found in 16 out of 75 (21%) women one year after mastectomy by Maguire *et al* (1978). Hopwood *et al* (1991) found 56 out of 211 (27%) women with advanced breast cancer were probable cases of an anxiety state and/or a depressive illness, assessed by the Hospital Anxiety and Depression Scale. Bereaved relatives reported that depression was present in 54% patients in the last week of life (Addington-Hall *et al* 1991), and in 38% of patients in the last year of life (Seale 1991a). Patients may have several symptoms, including depression. Discussion of this

study's findings with team members, suggests that depression may be present, but often was not recorded because it was not the main symptom.

Other psychological aspects, such as anger, loss, fear, shock, withdrawal, guilt, confusion and anticipatory grief also occur in terminal cancer, but are not measured by STAS (Cassidy 1986). Out of 192 patients referred to 12 hospice services in the U.K. professionals recorded the following psychological and social problems: in patients, anxiety 62%, depression 36%, anger 14%, withdrawal 26%, denial 21%, guilt 2%, mental confusion 21%; in carers, anxiety 63%, depression 16%, anger 16%, withdrawal 6%, denial 9%, guilt 7%; and social problems: financial 14%, accommodation 21%, isolation 27%, domestic discord 14%, and care for dependents 8%. One or more emotional problems were reported in 67% of patients and 50% of carers (McCarthy 1990).

STAS includes only the more common psychological and social problems: patient anxiety, family anxiety, patient insight, family insight, financial and practical aids. Communication between patient and family may reflect domestic discord. For STAS to include further aspects, new items would be needed. Adding depression, as a separate item, would be useful given its low prevalence as the main symptom.

Many studies have reported only the presence or absence of depression and other psychological aspects, rather than severity.

The reports of professionals (as in McCarthy 1991) or the reports of family members (as in Seale 1991a and Addington-Hall *et al* 1991) were based on the respondents' own understanding of each term and recordings made in clinical practice. Only occasionally were standardised validated measures used. Many measures, for example the Hospital Anxiety and Depression Scale, or the Beck Depression Inventory, as discussed in the literature review, include some items which may not be suitable in palliative care. To develop further psychological items in STAS considerable testing would be required.

7.1.3 Other aspects of support team work not included in STAS

STAS reflects the patient and family orientated work of support teams, but not their other work, including bereavement care, formal education of other health professionals, and self-management of their service.

Finally, the STAS items are problem orientated and do not measure 'positive aspects' of dying to which the hospice movement often aspires. For example, the item 'wasted time' measures the amount of time a patient lost, but does not measure how 'productively' the patient uses their remaining time, rather than waiting for death. A chaplain suggested that the item 'spiritual' should also measure the amount which the patient gives, in spiritual terms, to the team.

7.1.4 Features of a good death which are not measured by STAS

The items were generated to measure the goals of support teams

when helping patients and families achieve a 'good' or 'appropriate' death. The STAS item 'planning' measures personal preparations, public preparations, and farewells, which were listed by Kellehear (1990) as features of a 'good death'. The feature 'awareness of dying' (Kellehear 1990) is measured by the STAS item 'insight'. However, Kellehear also proposed that 'good death' include a reduction in work and activities. This is not measured by STAS, and was not perceived as a goal by support teams.

STAS measures first parts of Weisman's (1977) definition of appropriate death (.i.e. absence of suffering, preservation of important relationships, relief of remaining conflicts), but it does not measure the later aspects - 'belief in timeliness, exercise of feasible options and activities, and consistency with physical limitations, all within the scope of one's ego ideal'. These features are highly individual. Great care would be needed to ensure that the team's view of 'good dying' was not imposed upon the patients, rather than Saunders' (1978) suggestion of: 'helping the patient to find his own way of dying, his own death'. STAS items can be regarded as pre-requisites for a patient (and family) to find his/her own way of dying. Without pain control, symptom control, good communication, the possibility for planning as the patient wishes etc., then a 'good death' within the patient and family's desires, cannot be achieved.

7.1.5 The wonder is, not that the field of stars is so vast, but that man has measured it. ***(Anatole France, Garden of Epicurus)***

This quotation suggests the danger of over-confidence in human's ability to accurately measure. The total impact of palliative care probably cannot be measured. Mount and Scott (1983) likened measuring hospice care to measuring the beauty of a rose. They commented:

> 'Consider the rose. You can weigh it, photograph it, categorise it, measure its height, petal size and number of thorns, not to mention the ratio or thorns to height. The mean and standard deviation of the measures can then be determined.... The colour may be determined by spectroscopic analysis; the chemical composition defined, the light refraction from the dew drop on the petal measured and aroma quantified (perhaps a group of descriptors similar to the Melzack Pain Ratings Index could be devised).....
>
> ... Although we would like to measure the beauty of a rose or to quantify the sense of fulfilment of a dying person we do not yet have the tools'.

Therefore, it would be surprising if STAS did not have weaknesses and omissions. One has to achieve a balance between limiting the number of items to those which the team or researcher can record and analyse, and developing a measure which covers the total impact. Teams can rarely record more than 17 items on a regular basis, and ideally, as shown in the later sections of this discussion, they prefer fewer items.

Another difficulty in adding STAS items is that these may range into areas beyond the competence of all members of the multi-disciplinary support team. STAS was designed so that any team member - social worker, doctor, nurse or other - could assess each item as part of the normal course of work. Providing a detailed assessment of symptom, psychological or social items, rather than just identifying a level of severity among common items, might prove difficult for team members without specialist training in this area. In practice, if the patient has mainly symptom problems then a doctor is usually the key worker and records the assessment, whereas if the problems are mainly social, the social worker would usually be the key worker. This would result in the specialised items being recorded for only those patients with problems.

7.2 Validity and reliability of STAS

This thesis also aimed to develop a measure which was valid and reliable. Face validity and content validity were demonstrated through presentations and discussions of STAS by palliative professionals, and by use of STAS in five settings.

7.2.1 Bias in recordings

STAS used assessments made directly by professionals and there may have been recording bias by the support teams. This problem is found in many medical and clinical audits which rely on ordinary clinical records. Hospital and community staff may give

different assessments of quality of life and symptoms compared with dying patients themselves (Slevin *et al* 1988, Mercier *et al* 1987, Wilkes 1984). Furthermore, as the team members become familiar with patients and their problems they may tend to rate the severity of items less severely.

To reduce bias in STAS recordings team members were encouraged to discuss their assessments together at the weekly meetings. They recognised that STAS offered an insight into the pattern of work and could indicate areas where care might be improved. Three points support the view that teams were making objective, rather than biased, assessments: they recorded different levels of need in different patients; changes in item ratings differed between patients, and could deteriorate despite team interventions (especially in the last week); and there was an association between STAS scores and service events (e.g. hospitalisation). However, these findings cannot rule out the possibility of systematic bias.

7.2.2 Criterion validity

Ratings of STAS items by patients, FMs and team members showed moderate agreements and correlations, but one view was clearly not an absolute reflection of another. The STAS item 'family anxiety' showed the lowest validity, suggesting that teams need to improve these assessments. Correlations between patient and team were similar to those between patient and FM, found in this study and others (r or rho ranged 0.40 - 0.63, see Hinton 1979, Slevin *et al* 1988). Thus, ratings from team members and FMs

appear to be equally close to patient's self-ratings.

Who is the ultimate criterion: patient, FM or team?

The results provide further information on the relationship between patient, FM and team assessments. This question of the ultimate criterion was raised in the literature review. Patients are proposed as the most valid assessors of their quality of life and health status (Baum *et al* 1990), providing they are well enough to respond to questions. However, the differences found in this work between patient, FM and support team shows that each has a different perspective. FMs tended to identify most problems, and patients the least, with the team ratings often between these two views. It may be that the patients wished to 'put on a brave face', and under-reported their problems. For the item 'patient anxiety', patients' self-reports were especially low. The validity of patient reports of their psychological state is often questioned, and in this area, psychological or psychiatric self-rating instruments are validated against a clinician's judgement (see Hill *et al* 1989 for a recent example). Similarly, when interviewing elderly or frail patients traditional interview material may be insufficient. Clark and Bowling (1990) found that observational methods were necessary to discriminate between long stay ward and nursing home care for elderly people. Spitzer (1987) argued that indices can be based on observation of a patient 'without eliciting information from the patient about how he or she feels at a given point in time'; and that there is good agreement

between these clinical observations and patient reports.

Patient reports have also been criticised because their scope of assessment is limited to their own experience, and they are unaware of the variation which can occur, or the circumstances of other individuals. Chimbira *et al* 1980 demonstrated that women's estimates of their menstrual blood loss as having been heavy, medium or light, bore no correlation with the actual blood loss measured, and suggests that this is because women have only their own expectations and experience as a criterion. Calman (1984) also suggests that a subject's view of quality of life is affected by their own expectations, hopes and past experience.

The results of criterion validity suggest that for the purposes of audit and measuring effectiveness, the STAS is sufficiently valid. However, given the drawbacks of all assessors, each study must choose the view most suitable for its aims.

7.2.3 Construct validity

Correlations between STAS and HRCA-QL supported the prior hypotheses of construct validity. There was convergent validity, demonstrated by correlations between STAS and HRCA-QL where items were similar for patients early in care. A STAS sub-scale of six items was correlated with the HRCA-QL total (rho = -0.45). The strongest correlations were between 'patient anxiety' (STAS) and outlook (HRCA-QL) and between 'other symptom control'(STAS) and health (HRCA-QL) in patients who were more than four weeks before

death (rho = -0.70 and rho = -0.64). Discriminant validity was demonstrated by the few weak correlations between the service items in STAS and HRCA-QL items. However, some unpredicted correlations were found. These made sense to clinicians, who would expect a patient referred in poor health, as indicated by HRCA-QL, to require more services, as indicated by STAS. Similarly, patients with poor mobility and ability to self care, as indicated by the HRCA-QL, had a greater need for practical aids, as indicated by STAS, at referral.

However, this thesis does not recommend HRCA-QL to measure cancer palliative care. Scores according to four out of the five items deteriorated in the last 11 weeks of life, irrespective of the patient's point of referral. At death most patients were rated zero. Only one item, support, was different, probably because it is affected partly by the number of FMs (and this rarely changes over a few weeks) and partly by the amount they visit the patient. Scores according to STAS did not show this deterioration towards death. These findings do not support the view of the National Hospice Study, that HRCA-QL is the best available measure for palliative care. The study suggests that STAS may be a more sensitive and appropriate measure.

7.2.4 Limitations of the validation

There are several criticisms of this validation of STAS:

1) The tests of face and content validity used the views of professionals and did not systematically collect the views of

patients and family members. The views of the general public were not collected. It would have been practically difficult to recruit and consult directly with a representative sample of dying patients. However, the STAS items were developed using the published and research evidence of the views of dying patients and their families.

2) In the criterion validation, because direct interviews with patients and FMs were used, only 7 of the 17 STAS items were compared. The validation of STAS against HRCA-QL concentrated on the patient-orientated items many of which overlapped with those considered in the interviews with patients and FMs. Interviews with other caring staff, or direct observation during care, would be needed to validate the other items.

3) Interviews were obtained with only half of all the patients in care. Similar research with dying patients has also found this problem (Ward 1985, Lunt and Neale 1985). Measurement of care of the dying which relies on information from patient interviews may be seriously affected by non-response bias. However, by using STAS, assessments can be completed on all patients in care, including those who are very sick and those who do not have family members.

4) Patients and FMs were interviewed once. Too few patients survived for a second interview to determine if changes according to STAS were also reported by patients and families.

5) The HRCA-QL index showed decreasing correlation with STAS items as death approached. It is possible that this lack of

correlation could be due only to a lack of congruence and differences in variance between the two measures: we do not know whether the HRCA-QL index and STAS have matching intervals throughout the whole span of their ratings.

6) STAS was compared only with one other instrument. It was not possible to compare STAS with other measures in this work because of the amount of time teams had available to make ratings. In hindsight, given the very low variation in HRCA-QL ratings at death, it would have been worth attempting to persuade the teams each to use one other measure in addition to STAS. When teams were recruited to the study it had not appeared they would agree to this, but greater efforts could have been made to persuade them.

It would be useful to compare STAS with the Hospital Anxiety and Depression Scale and the Cancer Inventory of Problem Situations or the Rotterdam Symptom Checklist despite their limitations and the uncertainly of normal responses in dying patients. Scales completed by external assessors might also be used. This would be a more expensive study and would be limited even more by missing data. Therefore, it is reasonable to delay such work until first studies have shown that STAS has acceptable validity, reliability and practicality. There may be some value in comparing STAS with new measures such as the 'Initial Assessment of Suffering in Terminal Illness', although such comparisons should wait until these measures have demonstrated validity and reliability.

The development of STAS did follow the stages outlined by Streiner and Norman (1989) and did meet the minimum criteria for validity suggested by Spitzer (1987):

a) the characteristics for validity and reliability were declared in advance

b) face and content validity were enhanced in development by invoking the views of professionals and interested groups

c) validity was tested with the types of patients among whom the STAS will eventually be used

d) construct validity considered convergent and discriminant validity.

7.2.5 Reliability

Enhancing reliability

To enhance reliability teams starting to use the STAS spent the first month of use discussing the STAS assessments for patients during the weekly meeting. As only new referrals were recruited to the study, the number of patients gradually increased. After the first month, when about half of patients in care were included in the audit, the teams discussed scores most relevant to management and those they were unsure of. During the training period and the subsequent ten scoring sessions, the researcher assisted any team member who was uncertain, and listened to the discussion of the scores. Clinical examples of individual scores were available to the teams.

When selecting the appropriate STAS ratings the patient's key worker consulted their own booklet containing the agreed definitions for each item. The booklet was developed during the pilot study, when it was clear this helped team members to make rapid assessments and improved their reliability.

Test-retest reliability

The criteria for test-retest reliability were satisfied for 16 out of 17 items, with Cohen's Kappa ranging 0.48-0.87, Spearman correlation coefficients ranging 0.65-0.94, and intraclass correlation coefficients ranging 0.41-0.95. Levels were similar to those accepted by Selby *et al* (1984) and to those recommended by Nunnally (1978). The items 'pain control' and 'symptom control' were amongst the most reliable in all tests, whereas the items 'professional anxiety' and 'advising professionals' were the least, although acceptable. As recommended by Spitzer (1987) reliability was verified by those for whom STAS was intended to be used.

The item 'predictability' did not reach the pre-set standards for reliability. Doctors and nurses cannot accurately predict survival (Forster and Lynn 1988, Evans and McCarthy 1985) and it may be that this item - which measured the prognostic needs of the patient and family - cannot be reliably assessed because of these difficulties in prognostication.

The results of the test-retest reliability were similar in the 40 patients covering a wide range of problems and severity, and in

the five patients with nine raters. Numbers were small but there was no discernible pattern of one staff group (e.g. doctors) rating differently from another staff group (e.g. nurses).

Internal consistency

Levels of internal consistency for ratings at death and at referral were similar to those found in other measures of a similar size, e.g. the Beck depression inventory (21 items), Cronbach's alpha = 0.81 (in non psychiatric patients) (Bowling 1991) or the Meaning of Life Scale (15 items), Cronbach's alpha = 0.78 (Warner and Williams 1987). Levels were higher than for the Symptoms of Anxiety and Depression Scale (Split half reliability = 0.61-0.69, Bedford *et al* 1976) and for the HRCA-QL index when tested in this analysis, but lower than the Sickness Impact Profile (0.81-0.97, Bergner *et al* 1976), although this measure has many more items than STAS (which would increase Cronbach's alpha). The levels for STAS are acceptable, especially because STAS contained diverse components of physical, emotional and social circumstances.

Levels of internal consistency were similar in the full 17 STAS items and the 16 items, and very slightly lower when 15 and 14 items were tested. This small difference could be due simply to the higher number of items tested, because increasing the number of items in a measure can increase the internal consistency recorded.

The internal consistency of STAS was higher when ratings were considered at only one point in care, e.g. at referral or at death, than when all weeks were combined. This is not surprising. The relationship between the STAS items would be expected to vary at different times in care, and this would reduce the homogenicity when ratings at all times were analysed. This finding has implications if the number of STAS items were to be reduced. Any principle component or factor analysis attempting to identify key items reflecting the total STAS would need to consider the differing relationship between STAS items at different points in care.

7.2.6 Limitations of the reliability testing

There may have been interrater variation due to differences in the content of interviews of different staff: this would not be detected through testing with simulated patients. This aspect of reliability is very difficult to assess (Fleiss 1981, Nunnally 1978), and in this study could only have been tested if patients had been interviewed by different staff. As discussed in the methods, this was not possible. However, the use of written descriptions may have provided the assessors with too much standard information. One way of avoiding this would have been to use tape recorded interviews (although this would have excluded visual information) or video recorded interviews. The latter would have been the ideal approach, but it was beyond the budget of this study and may not have been acceptable to patients who were in distress.

7.3 Practicality and value of using STAS

A further objective of this study was to test the practicality of the measure. The STAS was readily included within the work of support teams. On average it took less than an extra hour per week to record the ratings, which is less that the amount of time reported for several other audits (see Shaw 1989 for examples). This does not include the time needed to discuss the results and to plan future actions. However, teams would have liked fewer items, especially those with the most patients in care and shorter survivals of patients, who found STAS impinged on an already busy week.

An important benefit of using STAS was that it systematised thinking about the objectives and outcomes of care. By recording the measures themselves, teams found that they were able to improve their practice and thus complete the audit cycle.

The educational value was further demonstrated in the findings of poor control of dyspnoea. The results prompted teams to review their practice and to develop a protocol for patients with dyspnoea, based on a review of effective treatments. An algorithm to predict the patients at risk of terminal dyspnoea was formulated using data from the audit. One team then began treatment using the new protocol, and audited this using the STAS. The need to review the relief of family anxiety is now being considered.

7.4 Use of STAS in determinating the effectiveness of care: results of the audit

The final objective of this thesis was to determine if STAS could be used to assess the effectiveness of care in different support teams, and to show when and where care was not effective. The results of the audit show that STAS provided valuable information on effectiveness.

7.4.1 Ability of teams to assess items

Missed assessments provide an insight into effectiveness, because it seemed likely that if teams were unable to assess an item they would be unlikely to meet the patient's or family's needs for that item.

Support teams found most difficulty in assessing financial and spiritual needs and frequently missed these assessments. Yet these elements of care are frequently stressed in palliative care literature (Saunders 1978, Mount and Scott 1983) and their potential rating was considered useful by at least some (if not all) members of the teams. Often team members expressed little confidence in their ability to assess spiritual needs, and they may need more training. There were differences between teams in items which could not be assessed, and one team in particular failed to assess these items, whereas another was very successful in completing the item 'spiritual', and another team was very successful in completing the item 'financial'.

Two hospital based teams missed the highest proportion of ratings relating to the family's needs. In discussion, these teams realised that often they had been unable to meet the FMs and had concentrated on the patient. The results suggest that these teams were failing to meet the hospice goal of considering the patient and family as the unit of care.

7.4.2 Changes in STAS ratings during care: effectiveness

There were significant improvements between referral and death for all STAS items. Although a large number of statistical tests were performed levels of significance were high (often $p < 0.00005$), making it unlikely that the differences found could have occurred by chance. The results support other studies showing improvements during support team care (Parkes 1980, Zimmer *et al* 1984, McCusker and Stoddard 1987). However, of four items showing a high initial need for care, three - symptom control, patient anxiety and family anxiety - improved by the second week of care but became more severe again in the last week of the patient's life. Teams were less effective in controlling these aspects, and they will need to test different interventions if care is to improve. Patients who were discharged showed a similar pattern of problems at referral but had less severe problems at discharge than those who died.

During care the total STAS ratings improved for the majority (82%) of patients, but deteriorated for one patient in six (16%). However, at death only 6% of patients had ratings which were

greater than 20, considered by teams to be clinically 'severe'. This compared to 33% at referral.

Pain was effectively controlled in most patients. Few studies have considered the degree of pain control by support teams. Parkes (1985) in a retrospective comparison of home, hospital and hospice care for cancer patients found that bereaved spouses reported higher levels of pain for patients at home, even when a support team had been involved in care. This study showed that pain control was improved after two weeks of support team care, and this was maintained until death.

However, the symptoms of dyspnoea and weakness were not improved during care - their prevalence as main symptoms and their severity were unchanged during care. This supported findings from the pilot study which had also indicated that dyspnoea was uncontrolled at death (see Appendix E which shows the results from the pilot study and compares these with other research). The prevalence of confusion as the main symptom increased during care. Studies of hospice care have tended to report the prevalence of symptoms on referral for care, and have rarely looked at subsequent control, except for pain (for examples see Hockley *et al* 1988, Wilkes 1984, Saunders 1978).

7.4.3 Limitations of effectiveness data

The results do not show whether patients would have fared better, or worse still, without support team intervention. This study

was not designed to test such hypotheses. The results do not show that teams caused the changes in a patient's condition. It is possible that events beyond the teams' control caused an improvement or a deterioration. Some items, for example 'patient insight', 'family insight' and 'predictability' may normally improve as death approaches. The analysis in section 6.2.3, which shows improvements for five STAS items in the 11 weeks before death irrespective of time in support team care, supports this theory. Teams noticed that occasionally ratings were dramatically altered by external events, for example the death of the nearest carer. Thus, the study was unable to measure outcomes, as defined by Donabedian (1980), which eliminate other causes for change.

The results do show where the goals of teams were effectively achieved and indicated where teams were not effective. The study also showed the difference between the actual outcome and the desired outcome, by showing items which remained severe at death. In a different study design, STAS could be used to assess palliative care in comparative settings, although such a study would have to overcome the difficulties of ensuring that representative patients were recruited, and that measurements were recorded equally in both groups.

The reaction of teams to completing STAS ratings is likely to result in a Hawthorne effect. Completing assessments made teams aware of items which remained severe. They would attempt to improve these problems, and thus their effectiveness may be

improved due to their participation in the audit. Teams valued the fact that STAS helped them to clarify problems and target their intervention. This educational and clinical benefit of STAS competed with the scientific need to measure true effectiveness. Because the audit was aimed to be educational, this Hawthorne effect was accepted. In other circumstances, where this effect would seriously reduce the value of the results, STAS ratings would need to be recorded by an independent observer.

A further problem was that previous ratings were known to team members when making assessments. These were not hidden for practical reasons: it would have been very time consuming to collect ratings from the team members each week. Teams wanted to see changes in score over time and use this information in their immediate working practice. It is possible that this made teams more likely to record a change in score. However, observation of the teams showed that when discussing patients they might agree that the patient's condition had changed slightly, but not sufficiently to record a different score. Guyatt *et al* 1989, in a randomised trial, found that if subjects knew their previous responses this did not affect the rating recorded.

Finally, for those items where a large number of ratings were zero, for example 'wasted time', STAS may have been insufficiently sensitive to change. It may be useful to re-grade the ratings for these items, expanding the definitions currently

within zero into the gradings of 0,1,2 and compressing the higher ratings into 3 and 4. However, it is very difficult to produce a measure which is both sensitive to small degrees of change and has a high degree of test-retest reliability, because these requirements tend to be mutually exclusive (Miller 1992).

7.4.4 Setting the results into the context of audit

Audit requires that standards are set. In this study it was accepted that the ideal standard for each item was a score of zero. This could be achieved for some items, but clearly not all. It may be that in repeating the audit the team would wish to set more realistic standards for some items. For example, a possible standard for family anxiety might be that less than 20% of families have ratings which are severe at death.

The work followed the requirements for formal audit (Shaw 1989). The STAS items formed the explicit criteria for outcomes, objective measurement was made of all patients, the results were reviewed by the team and other palliative care professionals and corrective action for some areas has been identified.

7.4.5 Utility of 17 STAS items for audit

Of the 17 STAS items, two may be less useful for audit. 'Patient insight' and 'family insight' are not goals which the teams always seek to improve, despite these being included by Kellehear (1990) in the features of a good death. Recent evidence suggested that patients and families should determine the pace at which their insight develops (Maguire and Faulkner

1988b). Observation showed that the teams created opportunities for diagnosis and prognosis to be discussed, but they would not seek actively to alter insight unless the patient asked for information. Nevertheless, teams have been reluctant to remove these items from STAS, as they find a record of insight valuable in working practice.

7.4.5 Total STAS rating.

Although teams found a total STAS rating valuable, the simple summing of STAS items may not be appropriate: a rating of 3 for different items may not be of equal significance. For example, it might be argued that 'pain control' is more important than 'financial'. Teams were asked if they could weight the importance of STAS items. They were unable to agree on weights, or even an order of STAS items. They argued that the relative importance of items varied from patient to patient. STAS definitions had attempted to take this into account by including, in most, the effect of the problem on the patient. Thus, to some extent, these reflected the importance of each item to each patient. This is supported by evidence from the audit results. The most severe items - family anxiety, patient anxiety, and symptom control - were in accordance with the common experience of palliative care that symptom control and anxiety of the patient and family are the most prominent needs of patients. The total ratings were also most strongly correlated with these items.

7.5 Future work

This work represents the first stages in developing a measure and the results found here would need to be replicated by testing STAS in other support teams, and repeating the work on validity and reliability. As discussed, it would be helpful to compare STAS with other measures, and to discuss its content more widely, including if possible patient representatives.

The weighting of items to develop a total score, and the reduction of STAS to a few key items could be considered further through consultation with team staff and further analysis of these results using principle components or factor analysis. Teams have indicated they would like to record fewer items. However, the analysis would have to take into account the changing relationships of STAS items during care. Discussion with the teams has indicated core items are most useful in practice - pain control, symptom control, patient anxiety, family anxiety, patient insight, family insight, one or two of the communication items, and practical aid. (These items also had the more rigorous testing of validity.) Any reduction of STAS should aim to include items of immediate utility, because this will encourage accurate recording.

An alternative to reducing the number of items would be to reduce the frequency of recordings from weekly to fortnightly or even only at referral and death. This may be advisable, for it has proved difficult to analyse the data from interim weeks, because

patients spent different amounts of time in care. How much recording time this would save is not clear: the ratings for interim weeks were the easiest and quickest to complete. Teams would also need a system to indicate when a rating was due for completion.

Analysis of the STAS ratings against further information on the process and structure of care could begin to answer some of the questions posed in the literature review of: what kinds of palliative interventions, by whom, for what patients and families are most effective. The characteristics of patients referred showed that teams saw very different groups of patients, and districts will clearly wish to ensure that they have a service which is accessible to those patients who will benefit most.

7.6 Adaptations of STAS

STAS has been recently adapted to audit the care of patients with HIV/AIDS, using fortnightly recording. The approach is also being used to develop instruments to audit other community services, since many of the items (e.g. symptom control, family anxiety, practical aid, communication) are relevant to many different services.

STAS was also used in a study to determine whether all patients in need of palliative care within the district were receiving it. Barnett and McCarthy (1987) identified patients using cancer registries and assessed these using the STAS. Although some

patients were well cared for by the existing primary medical care services, others remained in severe difficulties undiscovered by both general practitioners and hospital doctors.

Nottcut and Jacoby (personal communication), in Norfolk, recorded STAS assessments on patients and FMs using an independent researcher who observed the visits made by the support team. Their ratings were very similar to those found in this work, and similar aspects of work were most and least effective.

In-patient hospices have considered which items of STAS would be most relevant to their work. Symptom items would need to be extended, but service items relating to home care and the advisory nature of support teams are not needed. The Working Group of the Research Unit of the Royal College of Physicians (1991) recommended STAS as a measure for in-patient hospices and support teams to determine whether they successfully addressed the problems on admission.

STAS has made a beginning in an area where measurement is difficult, and it contains core elements important to palliative care which can be assessed by the multi-disciplinary support team. Approximately ten home care or in-patient units are now considering how they can test or use the STAS, either in its full form, or a reduced form, or with extra items they wish to develop (for example see Mant 1991). Providing any changes

attempt to ensure validity and reliability, eventually a small array of useful measures, covering various dimensions of palliative care, may develop. Different measures will suit the different purpose of the investigator, as for quality of life measures in cancer patients.

8. SUMMARY OF CONCLUSIONS

1. STAS items are suitable as outcome measures for palliative care and they reflect many of the patient and family orientated goals of support teams, although all aspects of a good or appropriate death are not included.

2. STAS items have face, content and consensus validity

3. STAS has reasonable criterion validity when compared with ratings from patient and FMs, although only 7 out of 17 items were tested.

4. STAS is demonstrated to have both convergent and discriminant validity when testing construct validity by comparing STAS ratings with those according to the HRCA-QL.

5. Inter-rater reliability for STAS is acceptable for 16 out of 17 items, but the item 'predictability' should be removed unless its reliability can be improved.

6. STAS has reasonable internal consistency for a scale of this size and diversity.

7. STAS is practical for use by support teams and recordings can be made as part of normal care.

8. STAS ratings discriminate between patients with many and few problems and indicate where teams are not effective.

9. The characteristics of patients referred to teams varied significantly.

10. During care ratings for all items improved significantly, but three items - family anxiety, symptom control, and patient anxiety - remained severe at death, and deteriorated between the second week of care and death.

11. Teams found most difficulty in assessing spiritual and financial items and some staff may need further training in these.

12. Dyspnoea and weakness were not controlled by support teams.

13. There were differences between the assessments of patients, FMs and support teams. Patients usually gave the least severe ratings and FMs the most severe.

14. The HRCA-QL is not recommended to measure palliative care.

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Appendix A

Meetings where study methods, STAS, and findings from pilot study were presented and discussed

Annual Scientific meeting of the Society for Social Medicine, Liverpool (1985).

Symposium. Recent Advances in Terminal Care, Leicester (1986).

Workshop: 'How do we evaluate our work?', Leicester (1986).

Grand round, University College Hospital, London (1986).

St Joseph's Hospice, London (1986).

Help the Hospices executive committee (1986).

Day Conference 'New Frontiers in Epidemiology and Community Medicine', The Royal Society of Medicine, London (1987).

The Wales and West Hospice Care Symposium, Cardiff (1987).

Workshop of Hospital Support Teams, St Christopher's Hospice, London (1987).

'Good Practices in Terminal Care Seminar', North East Thames Regional Health Authority, London (1987).

Prince and Princess of Wales Hospice First International Conference on Multidisciplinary Aspects of Terminal Care, Glasgow (1987).

Psychiatrists in Terminal Care Group, Leicester (1987).

Ty Olwen Hospice, Swansea (1987).

Countess Mountbatten Hospice, Southampton (1987).

'Care of the Dying' study day: The Queen's Institute, London (1987).

There were also informal meetings with other hospice teams.

Appendix B

Areas of work of support teams

Summary Description - Team A

Population receiving Support Team Care

Terminally ill cancer patients (and their carers/relatives) living in the health district, who are referred by a hospital consultant, general practitioner, or by hospital or community staff with the consultant or general practitioners' consent.

Members of Team

2 nursing sisters specialised in oncology
1 social worker
1 part-time clinical assistant (5 sessions per week)
1 secretary/administrator
1 consultant in radiotherapy "in charge" (1 session per week)

Methods of Working

Multidisciplinary team approach:

- individual or joint visits to patients and relatives/carers

- combined policy discussions, after visits, on assessment, and future needs

- formal weekly group review of all cases

- shared work-load and problems

- mutual support.

Areas of work

1. **Working Assessment:**

   - performed by all team members
   - for all patients and families/friends,
   - continual

of - strength and weakness
   - previous coping mechanisms
   - needs

Decide - how much to do, whether need involvement
       - influences, input of 2-7, which and when

2. **Emotional Support:**

- performed by all team members
- for family and patient

3. **Co-ordination:**

- performed by all team members
- for patient and family and professionals

Work
- liaise between patient and Dr./nurse/ward, etc.
- patient's "mouth-piece""
- give health professionals information patient has chosen not to give

4. **Symptom Control:**

- performed mainly by 2 Sisters and Doctor
- for all patients

- listen to origin of symptoms
- medication

5. **Organisation of Facilities:**

- performed mainly by social workers and nurses
- for all patients and families

- to provide practical needs and financial benefits.

6. **Bereavement Counselling:**

- performed mainly by social workers
- follow-up of family

7. **Advice and Education:**

- performed by all team members
- for other health professionals and social workers, etc on all aspects as above
- for family and patient.

Appendix C

SUPPORT TEAM ASSESSMENT SCHEDULE

GENERAL POINTS

The problem and need for improvement is scored on a 5 point (0-4) scale at first contact, then weekly until death.

High scores indicate many problems, low scores few problems.

Family = the patient's nearest carer.

Other professionals = the other involved professionals including General Practitioner, District Nurse, Social Worker, Hospital Staff.

Record 9 if you are unable to assess an item to indicate a missing score.

Record 8 if the item is not applicable. (E.g. When scoring family anxiety if there is no carer.) This indicates a different missing score.

Do not include 8s or 9s when calculating a total score. If 9 is recorded use the first available score for that item. If 8 is recorded assume the score for that item is zero.

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PAIN CONTROL

Effect of his/her pain on the patient.

0 = none

1 = Occasional or grumbling single pain. Patient is not bothered to be rid of symptom.

2 = Moderate distress, occasional bad days, pain limits some activity possible within extent of disease

3 = Severe pain present often. Activities and concentration markedly affected by pain.

4 = Severe and continuous overwhelming pain. Unable to think of other matters.

OTHER SYMPTOM CONTROL

Effect of his/her symptoms on the patient (not including pain).

0 = none

1 = Occasional or grumbling single or few symptom(s). Patient has usual activity and is not bothered to be rid of symptom.

2 = Moderate distress, occasional bad days, symptoms limit some activity possible within extent of disease

3 = Severe symptom(s) present often. Activities and concentration markedly affected by symptom(s).

4 = Severe and continuous overwhelming symptom(s). Unable to think of other matters.

PATIENT ANXIETY

Effect of his/her anxiety on the patient.

0 = None

1 = Worry over changes. No physical or behavioural symptoms of anxiety. Concentration not affected.

2 = Waiting for changes or problems: on edge. Occasional physical or behavioural symptoms of anxiety.

3 = Anxious often. Physical/behavioural symptoms. Concentration markedly affected.

4 = Completely and continuously preoccupied with anxiety and worries. Unable to think of other matters.

FAMILY ANXIETY

Effect of anxiety on the family.

0 = None

1 = Worry over changes. No physical or behavioural symptoms of anxiety. Concentration not affected.

2 = Waiting for changes or problems: on edge. Occasional physical or behavioural symptoms of anxiety.

3 = Anxious often. Physical/behavioural symptoms. Concentration markedly affected.

4 = Completely and continuously preoccupied with anxiety and worries. Unable to think of other matters.

PATIENT INSIGHT

Patient's awareness of his/her prognosis.

0 = Full awareness of prognosis.

1 = Prognosis over or under estimated by up to 200%. E.g. Thinking the prognosis is 6 months when it is likely to be 2-3.

2 = Uncertain over becoming well or long prognosis. E.g. 'Some people with this die and I might too soon.'

3 = Unrealistic. E.g. Expecting to return to normal activity or work for a year when the prognosis is only 3 months.

4 = Expecting to become completely well.

FAMILY INSIGHT

Family's awareness of the prognosis.

0 = Full awareness of prognosis.

1 = Prognosis over or under estimated by up to 200%. E.g. Thinking the prognosis is 6 months when it is likely to be 2-3.

2 = Uncertain over patient becoming well or long prognosis. E.g. ' Some people with this die and he/she might too.'

3 = Unrealistic. E.g. Expecting to return to normal activity or work for a year when the time scale is only 3 months.

4 = Expecting the patient to become completely well.

PREDICTABILITY (Need to predict)

Patient and family's need to know likely future events, sequence and time scale related to the team's ability to provide this information.

0 = Patient and family need no more information now or in near future: team able to predict future needs or unnecessary.

1 = Sequence of events unclear, prognosis and major events predicted.

2 = Prognosis within range and patient or family need to know exactly. May also need more information on sequence of events. E.g. Family can manage at home for 2 weeks but not for 4 weeks.

3 = Prognosis unpredictable over several months , likely events and problems unclear. Patient or family need this information

4 = No idea of likely disease progression, future needs or arrangements. Patient or family need some information.

PLANNING

Further need for the patient, as desired, to organize his/her affairs and special meetings.

0 = Completed or unnecessary.

1 = 1 aspect needs planning, not urgent, may be already underway.

2 = 1 aspect needs planning urgently / several aspects with some time available, may have been discussed.

3 = Major decisions to be made, urgent, patient has time to contribute and may have begun to think of these.

4 = Major decisions outstanding, muddled, very little time to plan or make arrangements. E.g. Deterioration or death imminent.

PRACTICAL AID

Further need for practical aids at home, reflecting the difficulty for patient and family without aids.

0 = None needed.

1 = 1 aid desirable, not urgent, patient managing present.

2 = 1 aid needed urgently ie. the next day, or a few aids needed soon, patient or family experiencing some difficulty.

3 = Aids needed badly, some improvisation possible.

4 = Patient incapacitated without basic aids.

FINANCIAL

Further need for entitled benefits, reflecting the difficulty for patient and family without benefits.

0 = All entitled benefits received, managing.

1 = 1 benefit desirable, patient and family managing, matter may be in hand.

2 = 1 benefit required urgently / several benefits desirable, patient and family experiencing difficulties in managing.

3 = Urgent need for several benefits, barely managing.

4 = Not managing, entitled to many benefits, in chaos and none in hand.

WASTED TIME

Amount of patient's time lost for tests or appointments which could have been avoided, the patient not wishing to attend.

0 = No time lost.

1 = 1 - 3 hours lost. E.g. Trip for prescription which tired patient.

2 = Half to one day wasted. E.g. Out-patient appointment.

3 = One + day wasted.

4 = Two + days wasted. E.g. Unnecessary or prolonged admission, results lost and repeated etc.

SPIRITUAL

Effect of any crises in beliefs, faiths or religious practices on the patient.

0 = Content in own spiritual beliefs, without feelings of guilt or punishment over illness. Any denomination or agnostic.

1 = Occasional doubts or unrealistic expectations. Patient able to resolve their feelings themselves.

2 = Uncertain, sometimes troubled. Doubts. Patient unable to resolve their feelings/problems themselves.

3 = Uncertain and guilty. Many be troubles, have conflicts, worry.

4 = Distraught with uncertainty or guilt over beliefs. In chaos as to how to remedy situation.

COMMUNICATION BETWEEN PATIENT AND FAMILY

Depth and openness of communication between patient and family.

0 = Communicating openly and honestly. Verbally and non verbally.

1 = Communicating openly at some times or with some family members.

2 = Acknowledge condition but discussion does not satisfy either the patient or family who feels full implications are not discussed.

3 = Out of step, all discussions guarded.

4 = Pretending.

COMMUNICATION BETWEEN PROFESSIONALS

Speed, accuracy and depth of information communicated between other professionals, reflecting any difficulties for patient and family.

0 = Detailed correct messages to all involved on the same day.

1 = Correct messages between key professionals, minor inaccuracies and delays between others.

2 = Small changes in management not communicated / major changes delayed for over 1 day, between key professionals.

3 = Delay of several days - 1 week before major changes notified. E.g. Hospital to General Practitioner.

4 = Prolonged delays or no communication, professionals unsure of which other professionals are visiting and when.

COMMUNICATION PROFESSIONAL TO PATIENT AND FAMILY

Depth of information given to patient and family, when they require this, from other professionals.

0 = Full information. Patient and family feel free to ask.

1 = Information communicated but not clearly understood.

2 = Facts given on request, patient or family would have liked more information.

3 = Evasive, avoids true picture or some questions.

4 = Avoids answering questions or visiting / gives incorrect information which distresses patient and family.

PROFESSIONAL ANXIETY

Effect of anxiety on other professionals reflecting any difficulties this causes for patient and family.

0 = None.

1 = 1 professional anxious. No inappropriate action.

2 = 1 or more professional(s) anxious, beginning to lose objectivity.

3 = Professional(s) stressed, multiple telephone calls, inappropriate action.

4 = Multiple indiscriminate referrals / want patient taken over / total paralysis.

ADVISING PROFESSIONALS

Amount and speed of advice needed for other professionals.

0 = No further advice needed.

1 = 1 professional needs advising within one week.

2 = 1 professional needs advising in 1-2 days / 2 + professionals need advising within one week.

3 = Urgent / immediate advice needed for several professionals.

4 = Major difficulties of patient and family not recognised by key professionals.

Appendix F

Questionnaire used when interviewing patients to collect independent STAS ratings

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STRICTLY CONFIDENTIAL

We are working in several health districts trying to find out more about people's health problems and their need for health services. This survey will help in planning health services for the future.

We have contacted you because we are particularly interested in people who have had recent contact with the support team or with the hospital.

In this booklet there are a series of questions about any symptoms you have and any worries you or your family face. There are also questions about the services you are in contact with. Please answer as many questions as you can. Even if you are only able to complete a few questions the information will still be very useful.

The information you give is in strictest confidence. Your views and opinions will be recorded anonymously. The researchers who are interviewing people are Irene Higginson (a medical doctor) and Jan Lloyd (a nurse volunteer).

We would like to thank you very much for taking the time and trouble to help us in this survey.

BACKGROUND INFORMATION Date of survey _____

1. What is your age? _____

2. What is your occupation? _____

3. When did you last have contact with:

   a) the support team? _____

   b) your family doctor? _____

   c) your hospital doctor(s)?_____

The next section asks how you have been over the last week

Please answer referring to the last week, only:.

4. SYMPTOMS IN THE LAST WEEK

   a) PAIN

   Have you have any pain? Yes / No

   If NO please go on to section (c), if YES please continue

   b) What effect did your pain have on you? Please ring one of the below.

   0 = none

   1 = Occasional or grumbling single or few pains(aches). You are not bothered to be rid of the pain.

   2 = Moderate distress, occasional bad days.

   3 = Severe pain present often. Activities and concentration markedly affected by pain.

   4 = Severe and continuous overwhelming pain Unable to think of anything else.

   c) OTHER SYMPTOMS

   Have you have any other symptoms? Yes / No

   If NO please go on to question 5, if YES please continue

   d) What was your main symptom (not including pain)?

   _____

e) Were there any other symptoms? If so what were they?

_____

f) What effect did these symptoms (not including any pain) have on you? Please ring one of the below.

0 = none

1 = Occasional or grumbling single or few symptom(s). You are not bothered to be rid of the symptom.

2 = Moderate distress, occasional bad days.

3 = Severe symptom(s) present often. Activities and concentration markedly affected by symptom(s).

4 = Severe and continuous overwhelming symptom(s). Unable to think of anything else.

5. ANXIETY IN THE LAST WEEK

a) Have you have any anxiety or worries? Yes No

If NO please go on to question 6, if YES please continue

b) What was the main cause for your anxiety? _____

_____

c) Were there any other problems? If so what were these?_____

_____

d What effect did your anxiety have on you? Please ring one of the below.

0 = none

1 = Worry over any changes. Not affected in any other way.

2 = Feel you are waiting for changes or problems to happen. This affects your concentration sometimes.

3 = Anxious often. Concentration markedly affected. Sometimes it makes you feel queer, gives you symptoms.

4 = Continuously preoccupied. It completely absorbs you, can't think about anything else.

PLEASE TURN TO NEXT PAGE..

6. This question is about your NEAREST FAMILY MEMBER OR CARER, please go on to question 7 if this does not apply to you.

a) Who is your nearest family member or carer? Please ring:

Is he/she your: wife / husband / daughter / son / sister /

brother / friend / other relation /

none of these: _____

b) What is his / her occupation? _____

Think about the last week, only.

c) Do you think he/she had any anxiety or worries? Yes / No

If NO please go on to question 7, if YES please continue

d) What was the main cause for his/her anxiety? _____

_____

e) Were there any other problems? If so what were these?_____

_____.

f) What effect did his/her anxiety have on him/her? Please ring one of the below.

0 = none

1 = Worry over any changes. Not affected in any other way.

2 = He she was waiting for changes or problems to happen. This affected his/her concentration sometimes.

3 = Anxious often. Concentration markedly affected. Sometimes it gave him/ her symptoms.

4 = Continuously preoccupied. It completely absorbed him/her, couldn't think about anything else.

7. ANY TIME WASTED IN APPOINTMENTS OR TESTS.

a) In the last week do you feel you have wasted any time for appointments or tests (or as an inpatient) at the hospital or with your family doctor?

YES / NO

If NO please go on to question 8, if YES please continue

b) What was this for? _____

c) How much time did you waste? Please ring one of the below.

0 = No time lost.

1 = 1 - 3 hours lost. Eg. Trip for prescription which tired you.

2 = Half to one day wasted.

3 = One + day wasted.

4 = Two + days wasted.

40

8. ARE YOU ABLE TO GET OUT Please ring:

1 = on your own

2 = with help

3 = not at all

41

9. WHO COMES IN TO VISIT YOU AND HOW OFTEN?

a) Please list below all the people including doctors, nurses, social workers, friends and family visit you at home and how often they visit. You don't have to use their name, just say for example, friend, family doctor, support team etc. The list below may help you.

Person visiting	Number of times per week	or	per month
Relative			
Friend			
Nurse (other than support team)			
Social Worker (other than support team)			
Family Doctor			
Volunteer			
Member of the support team			
Other _____			

42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59

PLEASE TURN TO NEXT PAGE....

b) Is this enough? Is there anything else you would like?

c) Are there any practical aids or equipment which you think would help you or your family around the home. (Which you don't have?)

60

10. COMMUNICATION

a) Who has talked with you about your illness? Please tick below:

No-one has discussed illness — 61
Family doctor — 62
Support team — 63
Hospital doctor — 64
Hospital nurses — 65
Your nearest relative/friend — 66
Another family member — 67
A friend — 68
Other _____

b) Who talked with you first?

_____ 69

The next 2 questions ask about communication in the last week

c) With the Support Team. When you talked with the support team members in the last week how did you feel about the depth of information they gave to you and your family about matters you wanted to know Please ring one of the below.

70

0 = Gave full information and you felt free to ask.

1 = Information given but not clearly understood. It confused you.

2 = Facts given on request, you would have liked more information.

3 = Evasive, avoided some questions.

4 = Avoided answering questions or visiting.

d) With other Doctors and Nurses. When you think of other doctors and nurses with whom you have talked in the last week how did you feel about the depth of information they gave to you and your family about anything you wanted to know. Please ring one of the below.

0 = Gave full information and you felt free to ask. ☐ 71

1 = Information given but not clearly understood. It confused you.

2 = Facts given on request, you would have liked more information.

3 = Evasive, avoided some questions.

4 = Avoided answering questions or visiting.

11. COMMENTS

a) Do you have any comments about the hospital doctors or nurses?

☐ 72

b) Do you have any comments about your family doctor or the district nurses?

i) Do you think your doctor is an easy person to talk to or not?

Easy	1
Not easy	2

ii) Do you think he/she has time to discuss things or not?

Has time	1
Not	2

iii) Would you describe him/her as:-

Very understanding	1
Fairly understanding	2
Not very understanding	3
Or what.....	

PLEASE TURN TO NEXT PAGE....

iv) Altogether would you describe the care from your family doctor as:

Excellent	1
Good	2
Fair	3
or Poor	4
(no Care)	5

[ ]33

c) Do you have any comments about the support team?

i) Do you think the support team are easy to talk to or not?

Easy	1
Not easy	2

ii) Do you think they have time to discuss things or not?

Has time	1
Not	2

iii)Would you describe them as:-

Very understanding	1
Fairly understanding	2
Not very understanding	3
Or what.....	

iv) Altogether would you describe the care from the support team as:-

Excellent	1
Good	2
Fair	3
or Poor	4
(no Care)	5

[ ]34

d) Do you think other people would be happy with the support team?

[ ]35

e) Do you have any other comments?

Appendix G

Questionnaire used when interviewing family members (FMs) to collect independent STAS rating

Department of Community Medicine

UNIVERSITY COLLEGE LONDON AND
THE MIDDLESEX HOSPITAL MEDICAL SCHOOL

66-72 GOWER STREET LONDON WC1E 6EA 5722

Professor M. G. Marmot

Telephone: 01-387 7050
Extn.
Direct Line: 388-

R

STRICTLY CONFIDENTIAL

We are working in your several health districts trying to find out more about people's health problems and their need for health services. This survey will help in planning health services for the future.

We have contacted you because we are particularly interested in people who have had recent contact with the support team or with the hospital. We are interested in the opinions of those who use the service and the opinions of their close relatives or friends.

In this booklet there are a series of questions about any symptoms your relative/friend has, and any worries your or he/she faces. There are also questions about the services he/she is in contact with. Please answer as many questions as you can. Even if you are only able to complete a few questions the information will still be very useful.

The information you give is in strictest confidence. Your views and opinions will be recorded anonymously. The researchers who are interviewing people are Irene Higginson (a medical doctor) and Jan Lloyd (a nurse volunteer).

We would like to thank you very much for taking the time and trouble to help us in this survey.

1

BACKGROUND INFORMATION Date of survey _____

1. What is your age? _____

2. What is your occupation? _____

3. When did you last have contact with:

   a) the support team? _____

   b) your relative/friend's family doctor? _____

   c) your relative/friend's hospital doctor(s)? _____

THE NEXT SECTION IS ABOUT YOUR RELATIVE / FRIEND

The questions ask how he/she has been over the last week

Please answer referring to the last week, only:

4. SYMPTOMS IN THE LAST WEEK

   a) PAIN

      Has he/she had any pain? Yes / No

   If NO please go on to section (c), if YES please continue

   b) What effect did his/her pain have on him/her? Please ring one of the below.

      0 = none

      1 = Occasional or grumbling single or few pains(aches). He/she was not bothered to be rid of the pain.

      2 = Moderate distress, occasional bad days.

      3 = Severe pain present often. Activities and concentration markedly affected by pain.

      4 = Severe and continuous overwhelming pain. Unable to think of anything else.

   c) OTHER SYMPTOMS

      Have he/she have any other symptoms? Yes / No

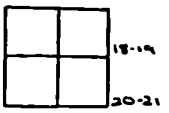
   If NO please go on to question 5, if YES please continue

   d) What was his/her main symptom (not including pain)?

   _____

e) Were there any other symptoms? If so what were they?

_____



f) What effect did these symptoms (not including any pain) have on him/her? Please ring one of the below.

0 = none

1 = Occasional or grumbling single or few symptom(s). He/she was not bothered to be rid of the symptom.

2 = Moderate distress, occasional bad days.

3 = Severe symptom(s) present often. Activities and concentration markedly affected by symptom(s).

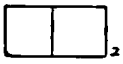
4 = Severe and continuous overwhelming symptom(s). Unable to think of anything else.

5. ANXIETY IN THE LAST WEEK

a) Do you think he/she had any anxiety or worries? Yes No

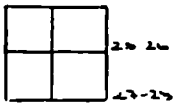
If NO please go on to question 6, if YES please continue

b) What was the main cause for his/her anxiety? _____



_____

c) Were there any other problems? If so what were these?_____



_____

d) What effect did his/her anxiety have on him/her? Please ring one of the below.

0 = none

1 = Worry over any changes. Not affected in any other way.

2 = He/she was waiting for changes or problems to happen. This affected his/her concentration sometimes.

3 = Anxious often. Concentration markedly affected. Sometimes it gave him/ her symptoms.

4 = Continuously preoccupied. It completely absorbed him/her, couldn't think about anything else.

PLEASE TURN TO NEXT PAGE..

9 30
9 31

6. This question is about yourself.

Think about the last week, only.

a) Have you had any anxiety or worries? Yes / No

If NO please go on to question 7, if YES please continue

b) What was the main cause for your anxiety? _____

_____ 32-33

c) Were there any other problems? If so what were these?_____

_____ 34-35 36-37

d) What effect did your anxiety have on you? Please ring one of the below.

0 = none 38

1 = Worry over any changes. Not affected in any other way.

2 = Feel you are waiting for changes or problems to happen. This affects your concentration sometimes.

3 = Anxious often. Concentration markedly affected. Sometimes it makes you feel queer, gives you symptoms.

4 = Continuously preoccupied. It completely absorbs you, can't think about anything else.

7. ANY TIME WASTED IN APPOINTMENTS OR TESTS.

a In the last week do you feel your relative/friend has wasted any time for appointments or tests (or as an inpatient) at the hospital or with his/her family doctor?

YES / NO

If NO please go on to question 8, if YES please continue

b) What was this for? _____ 39

c) How much time did he/she waste? Please ring one of the below.

0 = No time lost.

1 = 1 - 3 hours lost. Eg. Trip for prescription which tired him/her.

2 = Half to one day wasted.

3 = One + day wasted.

4 = Two + days wasted.

40

8. IS HE/SHE ABLE TO GET OUT Please ring:

1 = on his/her own

2 = with help

3 = not at all

41

9. WHO COMES IN TO VISIT YOUR RELATIVE/FRIEND AND HOW OFTEN?

a) Please list below all the people including doctors, nurses, social workers, friends and family visit him/her at home and how often they visit. You don't have to use their name, just say for example, friend, family doctor, support team etc. The list below may help you.

Person visiting	---------- Number of times per week	or	per month
Relative			
Friend			
Nurse (other than support team)			
Social Worker (other than support team)			
Family Doctor			
Volunteer			
Member of the support team			
Other _____			

42 51 52 53 54 55 56 57 58 59

PLEASE TURN TO NEXT PAGE....

b) Is this enough? Is there anything else you would like?

c) Are there any practical aids or equipment which you think would help you or your relative/friend around the home. (Which you don't have?)

60

10. COMMUNICATION

a) Who has talked with you about your relative/friend's illness? Please tick below:

61
No-one has discussed illness
62
Family doctor
63
Support team
64
Hospital doctor
65
Hospital nurses
66
Your relative/friend who is ill
67
Another family member
68
A friend
Other _____

b) Who talked with you first?

_____

69

The next two questions ask about communication in the last week

c) With the Support Team. When you talked with the support team members in the last week how did you feel about the depth of information they gave to you and your relative/friend about anything you wanted to know? Please ring one of the below.

70

0 = Gave full information and you felt free to ask.

1 = Information given but not clearly understood. It confused you.

2 = Facts given on request, you would have liked more information.

3 = Evasive, avoided some questions.

4 = Avoided answering questions or visiting.

d) With other Doctors and Nurses. When you think of other doctors and nurses with whom you have talked in the last week how did you feel about the depth of information they gave to you and your relative/friend about anything you wanted to know. Please ring one of the below.

0 = Gave full information and you felt free to ask.

1 = Information given but not clearly understood. It confused you. ☐

2 = Facts given on request, you would have liked more information.

3 = Evasive, avoided some questions.

4 = Avoided answering questions or visiting.

11. COMMENTS

a) Do you have any comments about the hospital doctors or nurses?

☐

b) Do you have any comments about your relative / friend's family doctor or the district nurses?

i) Do you think your relative / friend's doctor is an easy person to talk to or not?

Easy	1
Not easy	2

ii) Do you think he/she has time to discuss things or not?

Has time	1
Not	2

iii) Would you describe him/her as:-

Very understanding	1
Fairly understanding	2
Not very understanding	3
Or what.....	

PLEASE TURN TO NEXT PAGE....

iv) Altogether would you describe the care from your relative/friend's family doctor as:

Excellent	1
Good	2
Fair	3
or Poor	4
(no Care)	5

73

c) Do you have any comments about the support team?

i) Do you think the support team are easy to talk to or not?

Easy	1
Not easy	2

ii) Do you think they have time to discuss things or not?

Has time	1
Not	2

iii)Would you describe them as:-

Very understanding	1
Fairly understanding	2
Not very understanding	3
Or what.....	

iv) Altogether would you describe the care from the support team as:-

Excellent	1
Good	2
Fair	3
or Poor	4
(no Care)	5

74

d) Do you think other people would be happy with the support team?

e) Do you have any other comments?

Appendix H

THE HRCA-QUALITY OF LIFE INDEX

MOBILITY

During the past week the patient:

2 = has usually been able to walk (or propel wheelchair) in or outside of home and not restricted in climbing stairs (or using elevator if wheelchair bound).

1 = has been able to walk within home, but cannot climb stairs or walk long distance.

0 = has not been able to walk (or unable to propel wheelchair if on own)

DAILY LIVING

During the past week the patient:

2 = has been self-reliant in eating, washing, toileting and dressing, using public transport or driving own car

1 = has been requiring assistance (another person or special equipment) for daily activities and transport but performing light tasks

0 = has not been managing personal care nor light tasks and/or not leaving own home or institution at all

HEALTH

During the past week the patient:

2 = has been appearing to feel well or reporting feeling 'great' most of the time

1 = has been lacking energy or not feeling entirely 'up to par' more than just occasionally

0 = has been feeling very ill or 'lousy', seeming weak and washed out most of the time or was unconscious

SUPPORT

During the past week the patient:

2 = the patient has been having good relationships with others and receiving strong support from at least one family member and/or friend

1 = support received or perceived has been limited from family and friends and/or by the patient's condition

0 = support from family and friends occurred infrequently or only when absolutely necessary or patient was unconscious

OUTLOOK

During the past week the patient:

2 = has usually been appearing calm and positive in outlook, accepting and in control of personal circumstances, including surroundings

1 = has sometimes been troubled because not fully in control of personal circumstances or has been having periods of obvious anxiety or depression

0 = has been seriously confused or very frightened or consistently anxious and depressed or unconscious

THE KARNOFSKY INDEX

Modified to exclude 'need for hospitalization' from scores 30 and 20

100 = Normal, no complaints, no evidence of disease

90 = Able to carry on normal activity, minor signs or symptoms of disease

80 = Normal activity with effort, some signs or symptoms of disease

70 = Cares for self. Unable to carry on normal activity or to do active work

60 = Requires occasional assistance, but is able to care for most of his needs

50 = Requires considerable assistance and frequent care

40 = Disabled, requires special care and assistance

30 = Severely disabled

20 = Very sick, active support necessary

10 = Moribund, fatal process progressing rapidly

0 = Dead

Appendix I

Descriptions of 10 simulated patients used in reliability testing.

a) Seven patients where paired ratings were compared.

Simulated Patient to score. No. 2

Mr S is a 64 year old man with squamous cell carcinoma of the bronchus diagnosed 4 months ago. There are no known secondaries but the tumour occupies most of his right lung. He was not suitable for surgery and was treated with a short course of radiotherapy. He was referred from the out-patient clinic in radiotherapy as his shortness of breath had become worse in the last month. He is also a heavy smoker and has had chronic bronchitis for years.

The doctor referring him asks for help with symptom control and support for Mr. S's wife who he says is very anxious and is saying she 'cannot manage'.

You visit 2 days later. Mr S. lives at home with his wife in a council flat. They have one daughter living 10 miles away. Mr. S's main problem is shortness of breath. He is all right at rest but really can't make it to walk to the toilet or back. One trip to the toilet leaves him gasping and wheezing for about half an hour and his wife says he looks terrible. He also has problems washing and getting out of the bath. Mr. S also has a productive cough with clear sputum and he gets a sharp pain in his chest when he coughs. For the last week he says he has been coughing more, and the pain has been bad some days.

There are no practical aids at home and they have no telephone. There have been no district nurses going in and Mr. S's wife tells you tearfully that she just can't manage any more, and why isn't he getting better?

You ask Mr. S what the doctors told him in the hospital and Mr. S says that at first he was told he had a shadow on his lung but then it seemed to get better and since then nobody has told him anything very much. When his own general practitioner visited him last week when his cough started to get worse, he'd just said he was waiting for letters from the hospital and prescribed some antibiotics. Mr S's wife points out at this point that the prescriptions are very expensive these days and they really can't afford it. Mr.S's wife tells you that Mr. S has been really worried about money and hasn't been sleeping at night. They have just had a large gas bill which they can't afford to pay and Mr. S has been losing weight and his clothes don't fit. They have been receiving no benefits and Mr.S gave up his job when he became ill.

As you leave the house, Mr.S's wife stops you in the door and says tearfully "if he's not getting better you won't tell him will you? I know he's worrying about it but I don't want him to know, it would kill him".

Will you score what you can in the schedule - Thanks.

Simulated patient to score. No. 4

Mrs. P.

You are asked to see this 69 year old lady with cancer of the colon on the ward as they are planning to discharge her next week. She presented two weeks ago with bowel obstruction and now has a colostomy. The staff say she is recovering well but at operation was found to have liver and omental secondaries. Her liver is in fact very enlarged. The ward staff say Mrs P knows her diagnosis but does not know the disease is anywhere except her colon and her husband keeps asking them to promise they won't tell her. They say she doesn't really ask anything and her and her husband are a very private couple.

When you visit, Mrs. P has obviously lost quite a lot of weight and is complaining of anorexia, and especially nausea. She has no pain. The nausea troubles her most, she says it is there all the time and she can never quite forget it. It was worst before she had the operation, then became better, but in the last week has really troubled her and now she doesn't want to eat at all. She says that she is still feeling quite weak and is worried about how she will manage at home. However, the occupational therapist has visited her home and ordered various practical aids, and she will have a commode there although Mrs. P thinks she may not need it. The stoma nurse has also met Mrs P.

She describes her husband as "wonderful" and says he will do anything for her. He is retired now and at home the whole time. Her main fear, she says though, is feeling she is a burden to him and wondering if he will be able to manage. She is worried too if she will become obstructed again, as she doesn't want to "go through that again". They have planned a holiday abroad to visit their only son who lives in Ireland in 3 months' time. Mrs. P tells you she is hoping to get strong again so she and her husband can go.

When you ask what the doctors have told her about her illness Mrs P says they told her she had a growth in her bowel which they have removed and that she is doing very well. She says she can't understand why she is still getting the nausea. Then she asks why you have come to see her.

Just as you are leaving the ward her husband arrives and you have a quick chat with him on his own. He is quite doubtful about you

being involved and asks you "exactly what sort of patients do you care for?". He tells you that Mrs. P doesn't know about the disease in the liver and he has been trying to convince her that they managed to remove all of the tumour. He says he realises this is cancer and that she won't get better. He doesn't think that she should know and says he keeps encouraging her to get better, so they can go to visit their family. He says he is very worried about how they will manage at night. There are deputising services and before, he says, they had to wait 5 hours for anyone to visit when she was ill.

Please score what you can on the assessment schedule.

Simulated Patient to score. No 7

Mr Q is a 50 year old man with small cell carcinoma of the lung diagnosed 7 months ago. There are secondaries in the liver and bone. He was treated with chemotherapy and radiotherapy but is now not responding. He was referred from the out-patient clinic in radiotherapy because of marked deterioration in the last 2 weeks. He is also a heavy smoker and has chronic bronchitis.

The doctor referring him asks for help with symptom control and support for the patient and family. They have 3 teenage daughters, the youngest is 15 years old and still at home. One 17 years is at a technical college living 15 miles away and the 19 year old has recently got married and lives 5 miles away.

One day later the district nurses phone you also to make a referral for support for the family and symptom control. The general practitioner is happy for you to be involved. He tells you he is visiting Mr Q today and you arrange to visit tomorrow. He says Mr Q and his family know all about the disease and want him to be cared for at home. Mr Q is now deteriorating rapidly.

Mr and Mrs Q live in their own house in a small estate. You have another patient 3 doors down.

Mr Q is in bed when you visit. The bed is downstairs, and Mr Q is lying on a spenco mattress. He has a bed table, commode and urine bottle next to him.

Mr Q complains of pain in his right side, over the enlarged liver which radiates into his back. He describes the pain present nearly all the time. It was moderate until the day before last and then became worse. Yesterday his GP increased his morphine dose and he did manage a better night's sleep. The pain began again at 6.00 am today though. He also tells you that he has become slightly constipated in the last 2 days, and he would like something done about this.

Mr Q and his wife tell you they are only worried by the symptoms, but they don't know what to expect. Mrs Q says "we keep being on the look out for problems, on edge really; because we don't want any symptoms to build up". Mr Q and his wife sit together during the visit. Mr Q says "I don't want to think about how long I've got". When Mrs Q goes out of the room for a moment he adds "I'm just worried about how my wife and daughters will manage".

As Mrs Q comes back into the room she adds "one thing that worries me is when I go into the kitchen I can't hear if Bill (Mr Q) calls me. The rest of the time we are OK. The district nurses are lovely and are coming in every day now to help me with him; and my daughters visit at least once a day. Our family doctor says we can call him any time we like and he will come and visit, and he even told me I could go and see him on my own if I needed to."

You ask if you can help with anything else? Mr Q says he would like to know if you can help with a solicitor. This is his second marriage, he tells you and he does have a son from an earlier marriage who he wishes to trace and also have something in his will for. "I have a life insurance," he says, " and I want to leave a little of what my family will get to my son. I don't know where to find him though as I haven't seen him for 10 years."

Can you score what you can, thanks.

Simulated patient to score. No.12

Miss C

The general practitioner, Dr. Helpalot, rings you to refer this 75 year old lady who lives alone and has cancer of the pancreas. Miss C first presented 6 months ago with jaundice, she had a stent tube inserted and was fairly well until last month her tube blocked and became infected. This is now resolved, although she is still on antibiotics. However she is still deteriorating and feeling weaker. Dr. Helpalot has been visiting Mrs C weekly but he is just about to go on holiday and would like your help in the management and he also feels his partner won't be able to visit very much while he is away.

You visit a week later. Miss C lives in a warden aided flat on the ground floor. When you arrive the warden (Mrs Jolly) is having a cup of tea with her. Miss C is able to get up and about, although she is quite severely crippled with long term rheumatoid arthritis. She looks pale and slightly jaundiced. Her only symptom is itching at night. Most nights the itch keeps her awake for about an hour or more, but she usually manages to get off to sleep eventually. During the day she is fine and forgets about it. She has been using some calamine lotion that

Mrs Jolly got her from the chemist and that has helped. She has not tried anything else.

Miss C is very relaxed and cheerful. She tells you she has no more regular appointments with the hospital but she can go back any time she needs to. Dr. Helpalot and the warden are very kind and come if there is anything she needs. Her next of kin is a niece 80 miles away who she hasn't seen for 5 years and who doesn't know anything about her being ill.

"But Mrs Jolly knows I've got the cancer in my pancreas" she tells you. "I suppose I should contact my niece as it would be nice to see her some time. I've been out of touch so long I don't even know if she is still at that address."

Miss C has bath, mobility and seating aids fitted ages ago because of her rheumatoid arthritis. She has never had a telephone and she tells you she could afford one but she is not sure if she could manage to pull the dials round. However, she might manage the new push button dials. She tells you the warden is worried about her at night, in case she falls an can't get up. Her neighbour in the flats does pop in often though.

Please score what you can on the assessment schedule.

Simulated Patient NO.15

Mrs S. is a 69 year old married lady with adenocarcinoma of the lung which was diagnosed three months ago. At diagnosis, she was found to have secondaries in the bone, involving her left femur and spine. She has had chronic bronchitis for many years and was not suitable for surgery. Her femur and spine and lung were treated with radiotherapy. She is now referred by her general practitioner because of pain in the spine and some shortness of breath. She is a lady who has had depressive illness in the past but has a very supportive husband and two daughters who live round the corner.

When you visit, Mrs S. lives in a council house on the ground floor. One daughter is there as well as Mr S. Mrs S. tells you she has a pain in her left leg which has been better in the last week since her GP started MST Continus. However, she still has some bad days and was wondering if she could increase the dose. Also she is short of breath on exertion although she can manage to get around the house and do some housework. She has apparently lost quite a lot of weight lately. Her only other symptoms is loss of appetite, which is beginning to trouble her occasionally.

They have a telephone but in the bathroom you note that they probably could do with bath aids although they are managing fairly well at the moment. Mr S. is retired and is very keen to care for his wife.

Mrs S. tells you that she knows that she has cancer and she knows she knows that she will get worse, but she wants to remain at home for as long as possible. She tells you that her and her husband, who have been married for almost 50 years now, talk about everything.

Mrs S. tells you she is tired of going up to the hospital. She tells you that they are very nice there but the journey really wears her out. She went last four days ago. Although the doctor were very good and saw her quite quickly (so that she only had to wait for about half an hour) the journey there and back tired her out for most of the day.

They also have some financial worries. They have just had a large gas bill that they are going to have problems paying, and because of Mrs S's weight loss, her clothes don't fit and they can't really afford to buy any more. They are only just managing to buy food. They also tell you that they would like very much to go on holiday together, but can't afford it. The two daughters both have young families and are unable to help.

They like their general practitioner who has been very involved in Mrs S's care all along and they say that he has always been very frank with them. Mr S. does say he is worried sometimes about whether he will be able to manage at home although his daughters are very supportive. Mrs S. seems a little bit more calm. She tells you "I'm not worried about what will happen, - I don't believe in a god but I do know that we all have to go. However, I am concerned that my husband will be okay".

Will you score what you can in the schedule - thanks.

<u>Simulated Patient. No. 16</u>

Mr V. You were asked to see this 80 year old gentleman with cancer of the prostate on the ward to advise on symptom control and home support. He presented five months ago with secondaries in the bone and has been treated with hormones and radiotherapy. He lives alone and the ward staff who referred him are worried about how he will be able to manage. They tell you that they have told him that he has cancer but he really doesn't seem to be able to take it in.

Mr V. has 2 children. His son lives about five miles away and has had a heart attack in the past. His daughter lives nearer and has a teenage family.

Mr V. lives in a council flat on the third floor. There is a lift and there is quite a supportive neighbour who has popped in to see him while he has been on the ward. This time he was admitted because of bone pain but this has improved now and they are hoping to discharge him next week.

When you visit, Mr V. is quite a sprightly man. He has lost a fair bit of weight but has been walking round the ward and is self caring. He tells you he's very anxious to get home and anything you can do to help him he'd be really grateful. He tells you that he has occasional pain in his back, just a niggle now and then, but he has had arthritis for years and he doesn't really bother about it. It was bad a week or so ago, before he came into hospital but it's a lot better now.

He is a very independent man and tells you that he's had meals on wheels and home helps offered to him in the past, but he doesn't want them, thank you very much. He tells you his neighbour, Mrs K. does give him the odd meal now and then and that's very nice. He tells you he's not worried about anything except getting home. When you ask him what the doctors have told him about his illness, he tells you that they seem to think that he has cancer in his bones and that's whey he's on the hormone tablets and the radiotherapy to treat it. He tells you that he feels he's getting a lot better at the moment and that the treatment must be obviously working.

He becomes quite sad when he talks about his wife, who died five years ago. He tells you they had a very close relationship. He's not very fond of his son who lives five miles away. He says: "He's a bit of a crook really and he's just waiting for me to pop off to get my money".

"Mind you.." he adds, "he'll probably go first, as he's already had one heart attack".

His daughter, whom he gets on better with, comes to visit him when she can, usually twice a week and he likes his grand-children very much. However, he tells you that he really wouldn't want to go and stay with his daughter as they have a very small flat and with all the teenagers, it can get quite noisy and crowded. When you ask him what practical things he's got at home, he becomes very vague and tells you that really he doesn't want anything at all and that he can manage.

He tells you he likes the hospital ward very much. His own doctor, he tells you, is nearly his own age as well and has difficulty managing the stairs to his flat when the lift is broken so he doesn't visit very much.

He tells you that he wouldn't want to be at home if he was very ill - he would rather be in hospital. It says he hates the idea of being a burden to his daughter and neighbour.

Please score what you can on the assessment schedule - thanks.

Simulated Patient No. 18

Mr C. is a 75 year old married man who has been recently diagnosed as having cancer of the lung. Most of the lower lobe of his right lung is involved. He is referred by the ward who say that he is getting some pain in his chest but also there are many social problems as Mr C's wife is severely disabled following a stroke and he does all the caring for her. When you visit on the ward, Mr C. tells you that in fact his wife was admitted at the same time as him because she was unable to manage at home. He is quite a fit man who has been getting around the ward, but is complaining of right sided lower chest pain which occurs when he takes a deep breath. He tells you that sometimes it doesn't bother him too much but really he would like to be rid of this.

He tells you that his wife doesn't know that he has got cancer and he is very worried that he will not be able to look after her. He tells you that he is upset because he doesn't feel that the care on the ward where his wife is is as good as it could be and really he just wants to get better and get out so that he can look after her. In fact, he has been caring for his wife since she had her stroke two years ago. His wife is very disabled and is practically bed bound. She has a speech impairment but he tells you that she is "All there". You ask about his home and he tells you that they have lots of practical aids because of his wife. He actually lifts her in and out of bed and does all the practical care. He has been receiving attendance allowance for looking after his wife and a small pension from his work.

You talk about the future with him. He says that he is very worried about how his wife will be cared for if he gets more ill and he really doesn't know what they will do. They have no children and no other close relatives. He says that he hates the idea of her having to go in somewhere and he wants to manage at home for as long as possible, looking after her.

When you talk to the ward staff, there seemed to have been some muddled communication between the two wards where Mr and Mrs C. are. Mrs C's ward phoned over yesterday and said that the doctors had been round and said that she could go home. However, Mr C. is not yet ready to go home, he is still awaiting some more tests and the doctors are thinking of doing a plural tap as he has some fluid in his right lung. The ward staff on Mr C's ward were furious and although they have sorted it out now and Mrs C. is not going home at the moment, they are worried that there might be problems again.

Please score what you can on the Assessment Schedule, thank you.

b) Three patients where nine team members recorded ratings.

Simulated Patient NO.20.

Mrs E. is a 52 year old British widow referred by her general practitioner for support, especially for the 16 year old daughter who lives with Mrs E. in the council house.

Mrs E. presented one month ago with multiple liver secondaries from an unknown primary. She is now deteriorating. She has another daughter and a son, both with young families, and both living within 3 miles.

When you visit Mrs E. is lying on the bed in her night clothes. She is propped up against a back support because her back aches at times. She is not bothered by this because position relieves the ache. She complains of night sweats as her only symptom. Twice in the last week at night she has had to change the sheets, although she went back to sleep after. During the day she is fine.

She asks you a lot of questions about her illness. She was puzzled that at first the hospital doctors were trying to find her "cancer", but now they had given up. She says she found it difficult to ask them questions. They would answer (rather coldly and factually) if she asked, but they seemed so busy that she didn't feel able to. Her own doctor, although wanting to help, hadn't even been told she was discharged 3 days ago. She had telephoned him and he had been very surprised. He had had to telephone the hospital to find out what medication she had been put on. That meant that for two hours one morning she was on the telephone to the surgery trying to sort out her medication and she found this very tiring.

You agree to try and get hold of the hospital notes so you can tell her more about her illness. She says there are a lot of things to arrange; especially for her youngest daughter as she doesn't know where her daughter might live. She has discussed this with her eldest daughter but not her youngest daughter as she "doesn't want to worry her". She then asks you how long you think she has got. She says she thinks it might only be a eight to ten months.

She says she is worried about the future; especially over the uncertainty of what will happen and when. She was a practising catholic, but has lapsed in recent years and is wondering whether she might be able to contact the church. This troubles her at times.

She has no practical aids at all in the home and district nurses are needed. She is having a lot of trouble moving and washing herself, and she doesn't want her daughter to have to do this. She also finds her bed quite uncomfortable.

They also have financial worries. She becomes tearful and says they are at their wits end. In fact her daughter is down at the Citizen's Advice Bureau at the moment trying to sort out their income. Mrs E. did temporary secretarial work until one month ago and now they have no money coming in at all. Her older son and daughter have been trying to help out but they are short themselves.

When you arrive back at the office the youngest daughter telephones. She is very upset. She says her mother won't tell her what is going on and keeps pretending that she is getting better, but the daughter can see that she is not. The youngest daughter says angrily " they keep treating me like a child, as if I can't understand anything". The daughter says her father had a terrible death, he died suddenly of a heart attack at home and was in agony and then went blue and died. She says that she keeps imagining the same will happen to her mother. "She must be dying" the daughter says, "she looks so ill, and what will happen to me then?"

Please score what you can on the assessment schedule.... Thanks.

Simulated Patient to score. No.21

Mrs G is a 94 year old widow with cancer of the left breast diagnosed 6 years ago and treated with a mastectomy, radiotherapy, and tamoxifen. She was well until last month when she presented with a pathological fracture of her left humerus which was pinned. She now has widespread bony metastases in her pelvis, ribs and spine (L3,L4). She is referred by the out-patient department of the breast surgeons who ask for home support as she lives alone. They tell you Mrs G is happy for you to visit, and that it is "an early referral and not urgent".

You phone the general practitioner who says he is quite happy for you to be involved. He tells you Mrs G is a "delightful lady who knows exactly what is going on". She has no symptoms at the moment, and has said she doesn't want district nurses. She has a very good relationship with her home help though.

You visit 4 days later. The house is in a council estate on the ground floor. Mrs G and her tabby cat greet you at the door. She is a sprightly cheerful lady who tells you she is quite well and is managing the cleaning and cooking and getting out to do the shopping. She demonstrates walking round the house and says she she a grumbling pain in her back which only happens occasionally. She is taking Ibuprofen for this, and is quite happy. She has no other symptoms.

In the bathroom you notice that she has quite a low bath and no shower and Mrs G does say she has some problems getting in and out. She asks if a rail might help. You also notice that Mrs G does not have a telephone. She says she would like one but thinks that they are a terrible expense. However, she says that maybe she could see the point of it if she is ill.

Mrs G tells you that when she was first diagnosed as having cancer she wrote to her younger sister (82 years old) in Brighton and to her daughter in Australia. She had thought she was doing well and it was a great shock to her when her arm broke. However she says "you've got to go sometime and at my age it will either be the cancer that gets me or a heart attack. " She adds "Me and Sammy (the cat) are going to enjoy ourselves to the end though".

Then she shows you a stock of guinness in her cupboard. She says that her general practitioner suggested she had half a bottle each night to help her sleep. Apparently she'd been giving a bit to Sammy to help him sleep too!

She tells you that both her sister and daughter know now that the "cancer has now spread to my bones" and that her "days are numbered". Her daughter is visiting England next month and will be bringing her grandchildren. Mrs G says she has lots of friends from the local church who come in to see her and the local priest calls in each week. She adds " he even gave me the 'sacrament for the sick so I'm ready to go any time.

She gets on very well with her general practitioner, and is on first name terms with him. She has known him for years, she says, and has his home telephone number in case she has problems. He calls in anyway every one or two weeks. She describes him as a lovely down to earth man, who has always been quite straight with her.

Financially she tells you she is managing OK and has a widows pension from her husbands company. Towards the end of the interview Mrs G says she must stay at home for as long as possible to look after her cat, but she has been thinking that she might like to eventually go into a hospice if she was not well enough to manage at home. She wants to take the cat in with her and says she had arranged with one of her church visitors to look around a local one. She had a cousin who died in one 30 miles away and she was very impressed.

Can you score what you can on the assessment schedule.

Simulated Patient NO. 22

Mr F. is a 66 year old married gentleman referred by the radiotherapy senior registrar for pain control and because of likely impending deterioration.

Mr F. was diagnosed as having a squamous cell carcinoma of the left bronchus 18 months ago. He was initially treated with radiotherapy. The radiotherapist have been reviewing him in out-patients. The general practitioner is happy for you to visit and says that the radiotherapy registrar telephoned him after the last out-patient visit to let him know that Mr F. was deteriorating, and that they wanted to refer to the team. He says he had asked the family 2 weeks ago if the support team could be involved and they had said no - they didn't want to be reminded of Mr F.'s illness. Now they must have changed their minds. He adds that they are a very private couple, and last time he dropped in on them at home they were suspicious of why. He'd left if that they would call him if there were problems.

They live in a private, tree lined road, in a large house.

When you visit Mr F. is in bed. He is complain of severe and continuous pain in his head, which he says is agony. He has never known anything like this. He also has been vomiting all morning. His wife says the headache and nausea or vomiting in the morning had been getting worse over the last 10 days, but they didn't mention it to the doctors last time they were seen. Mr F. tells you if he is going to be like this his wants "to be put out of his misery".

Mrs F is in tears. She says he didn't like to ask the doctors about his headache because he was worrying it might be his cancer again. She says she just "can't cope", and that seeing him getting weaker is awful. She says she can't understand what is wrong because they both thought he had been cured.

They have a telephone, but no other practical aids. Mr F. has been almost completely bed bound and they have had to improvise using an old vase for a urinal, because he was too weak to get up to go to the toilet. They were thinking of going our to buy some aids but didn't know where to go. They have no financial worries and Mrs F. was thinking of getting a private nurse.

They have no close family or friends. They are very angry about Mr F.'s illness, and are asking why it should happen to them. Mrs F. tells you she has arranged for a spiritualist to come round, to make him get better.

As you leave Mrs F says she wished to doctors had never told Mr F. that he had cancer. She says it has done him no good at all and she is terrified that he will give up. He has been worrying all the time since the news and she says she thinks he is better when he doesn't know. She says "if this is a recurrence of the cancer you won't tell him will you it would kill him."

Please score what you can on the assessment schedule - thanks.

Appendix J. Ratings from team members for the 10 simulated patients.

a) Seven patients where paired ratings were compared

Simulated patient No.2

STAS ITEMS	Rater 1	Rater 2
Pain control	2	2
Symptom control	3	3
Patient anxiety	3	2
Family anxiety	3	3
Patient insight	2	2
Family insight	2	2
Predictability	2	2
Planning	2	3
Practical aid	3	3
Financial	3	2
Wasted time	0	9
Spiritual	9	9
Communication between patient and family	2	3
Communication between professionals	3	3
Communication professionals to patient and family	3	3
Professional anxiety	2	1
Advising professionals	3	3

Simulated patient No.4

STAS ITEMS	Rater 1	Rater 2
Pain control	0	0
Symptom control	3	3
Patient anxiety	2	3
Family anxiety	2	3
Patient insight	3	3
Family insight	0	1
Predictability	1	2
Planning	3	3
Practical aid	0	0
Financial	9	9
Wasted time	0	0
Spiritual	9	9
Communication between patient and family	3	4
Communication between professionals	1	1
Communication professionals to patient and family	3	3
Professional anxiety	1	1
Advising professionals	3	3

Simulated patient No.7

STAS ITEMS	Rater 1	Rater 2
Pain control	3	2
Symptom control	2	1
Patient anxiety	3	2
Family anxiety	3	2
Patient insight	2	1
Family insight	1	1
Predictability	1	1
Planning	2	2
Practical aid	1	1
Financial	0	0
Wasted time	0	9
Spiritual	9	9
Communication between patient and family	2	1
Communication between professionals	1	0
Communication professionals to patient and family	0	1
Professional anxiety	2	1
Advising professionals	1	0

Simulated patient No. 12

STAS ITEMS	Rater 1	Rater 2
Pain control	0	0
Symptom control	1	1
Patient anxiety	0	0
Family anxiety	9	9
Patient insight	0	0
Family insight	9	9
Predictability	1	1
Planning	1	1
Practical aid	0	0
Financial	0	0
Wasted time	0	0
Spiritual	9	9
Communication between patient and family	9	9
Communication between professionals	0	0
Communication professionals to patient and family	0	0
Professional anxiety	1	1
Advising professionals	0	0

Simulated patient No.15

STAS ITEMS	Rater 1	Rater 2
Pain control	2	2
Symptom control	2	2
Patient anxiety	1	2
Family anxiety	2	1
Patient insight	0	1
Family insight	0	9
Predictability	1	2
Planning	2	2
Practical aid	1	1
Financial	3	3
Wasted time	2	2
Spiritual	0	0
Communication between patient and family	0	0
Communication between professionals	9	9
Communication professionals to patient and family	0	0
Professional anxiety	1	0
Advising professionals	2	2

Simulated patient No.16

STAS ITEMS	Rater 1	Rater 2
Pain control	2	1
Symptom control	0	0
Patient anxiety	2	1
Family anxiety	9	9
Patient insight	3	2
Family insight	9	9
Predictability	3	4
Planning	1	2
Practical aid	9	9
Financial	9	9
Wasted time	0	0
Spiritual	9	9
Communication between patient and family	1	9
Communication between professionals	0	0
Communication professionals to patient and family	1	1
Professional anxiety	1	1
Advising professionals	1	2

Simulated patient No.18

STAS ITEMS	Rater 1	Rater 2
Pain control	2	2
Symptom control	0	0
Patient anxiety	2	1
Family anxiety	9	9
Patient insight	3	2
Family insight	9	9
Predictability	3	3
Planning	3	3
Practical aid	0	0
Financial	0	0
Wasted time	0	0
Spiritual	9	9
Communication between patient and family	3	4
Communication between professionals	3	2
Communication professionals to patient and family	3	3
Professional anxiety	2	3
Advising professionals	3	2

b) Three patients where nine team members recorded ratings

Simulated patient No.20

	R A T E R S								
STAS ITEMS	1	2	3	4	5	6	7	8	9
Pain control	1	1	1	1	1	1	1	1	1
Symptom control	2	2	1	1	2	2	1	2	2
Patient anxiety	3	2	2	3	3	2	3	4	3
Family anxiety	3	4	2	3	3	3	4	3	3
Patient insight	2	1	1	2	1	1	1	1	1
Family insight	2	0	2	2	1	1	2	2	1
Predictability	1	3	3	3	1	3	1	3	2
Planning	3	3	3	4	4	3	2	3	3
Practical aid	3	2	3	3	3	3	3	3	3
Financial	3	4	3	4	4	4	4	4	4
Wasted time	1	2	1	1	1	1	1	1	1
Spiritual	2	2	2	2	2	2	2	2	2
Communication between patient and family	3	1	2	1	3	3	1	3	3
Communication between professionals	3	2	3	3	4	3	3	3	3
Communication professionals to patient and family	2	3	2	3	3	2	4	3	3
Professional anxiety	1	1	1	1	2	1	1	3	1
Advising professionals	3	4	3	3	4	2	3	3	3

Simulated patient No.21

	RATERS								
STAS ITEMS	1	2	3	4	5	6	7	8	9
Pain control	1	1	1	1	1	1	1	1	1
Symptom control	0	0	0	0	0	0	0	1	0
Patient anxiety	2	0	1	0	0	0	0	0	0
Family anxiety	1	0	1	0	0	0	0	9	0
Patient insight	0	0	0	0	0	0	0	0	0
Family insight	1	0	1	0	0	0	0	9	0
Predictability	1	1	1	1	0	1	0	0	1
Planning	1	1	1	1	1	1	0	1	1
Practical aid	1	2	2	2	2	2	1	1	2
Financial	0	0	0	0	1	0	0	0	0
Wasted time	0	0	0	0	0	0	0	0	0
Spiritual	0	0	0	0	0	0	0	0	0
Communication between patient and family	1	0	0	0	0	1	0	0	0
Communication between professionals	0	0	0	0	0	0	0	0	0
Communication professionals to patient and family	0	0	0	0	0	0	0	0	0
Professional anxiety	0	0	0	0	1	0	0	0	0
Advising professionals	1	1	2	1	2	2	1	0	1

Simulated patient No.22

	RATERS								
STAS ITEMS	1	2	3	4	5	6	7	8	9
Pain control	4	4	3	4	4	3	3	4	4
Symptom control	4	3	4	3	3	3	3	4	3
Patient anxiety	2	3	3	3	4	4	3	4	3
Family anxiety	4	4	4	3	4	3	2	4	4
Patient insight	3	3	1	2	4	3	2	2	4
Family insight	1	3	2	2	3	3	2	3	4
Predictability	4	1	2	3	3	1	1	3	1
Planning	3	3	2	3	3	3	2	3	3
Practical aid	3	3	3	3	4	3	4	4	3
Financial	0	0	0	0	0	0	0	0	0
Wasted time	0	2	0	0	0	0	0	0	0
Spiritual	2	4	2	2	2	9	4	9	9
Communication between patient and family	3	4	3	4	4	3	1	4	4
Communication between professionals	1	2	1	1	1	0	1	1	0
Communication professionals to patient and family	1	0	1	1	2	1	2	1	1
Professional anxiety	0	1	1	1	1	1	1	1	1
Advising professionals	4	3	2	2	2	3	4	3	2

Appendix K

Clinical records from teams

Note - these have been reduced to fit within the margins of this report

Team A

NAME
DATE OF BIRTH
ADDRESS

SEX M / F
AGE
ACCESS ROUTE

Post code 1. NW1 2. W1 3. NW5 4. NW6 5. WC1 6. WC2 7. Other-

PHONE NUMBER

Status 1. Married 2. Widowed 3. Divorced / Separated 4. Single 5. Other
Nationality 1. British 2. Irish 3. Greek 4. Italian 5. Asian 8. Other
Religion 1. C / E 2. R. Catholic 3. Greek Orthodox 4. Jewish 5. Other Religion
6. Atheist 7. Agnostic
LIVING ALONE
OR LIVING WITH 1 2 3 4 >5 OTHERS

NEAREST CARER
RELATION 1. Wife 2. Husband 3. Daughter 4. Son 5. Sister 6. Brother 7. Friend 8. Other
ADDRESS

WORK 1. Part / 2. Full-time
3. No Job / 4. Retired
Carer's Karnofsky

PHONE NUMBER
KEY RELATIVES OR OTHER FRIENDS

G.P. ADDRESS PHONE NO.	HOSPITAL NUMBER HOSPITAL WARD CONSULTANTS
DISTRICT NURSES HV / GV	OTHER HOSPITAL STAFF
SOCIAL WORKER SOCIAL SERVICES / OTHER AGENCIES	HOSPITAL SOCIAL WORKER

DIAGNOSIS

DATE FIRST DIAGNOSED

METASTASIS 1. 2.

OTHER DIAGNOSES CAUSING SYMPTOMS

1.

2.

DISEASE SITE MOST ACTIVE 1. PRIMARY SITE
2. METASTASIS
3. OTHER DIAGNOSIS

REFERRED BY 1. GP 2. Radiotherapist 3. Oncologist 4. Surgeon 5. Physician 6. Other

NAME

DATE OF REFERRAL

Time diagnosis to referral: (1) 0-1 mth (2) 1-3 mths (3) 3-6 mths (4) 6 mths - 1 year (5) 1-2 yrs
(6) 2-3 yrs (7) 3-5 yrs (8) 5+ yrs

DATE FIRST SEEN

REASONS FOR REFERRAL 1.

2.

OTHER MAIN PROBLEMS AT REFERRAL

DRUGS AT REFERRAL

NOTES / OTHER RELEVANT INFORMATION

P. Weeks: from to

NAME: TEAM NO:

DATE OF FIRST ASSESSMENT:

HISTORY OF PRESENT ILLNESS:

RELEVANT PAST MEDICAL HISTORY:

SOCIAL CIRCUMSTANCES:

ACCOMMODATION: 1. Owner occupied 2. Private rented 3. Council 4. Hostel 5. Other

ACCESS : 1. Ground floor 2. By lift 3. By stairs

PSYCHOSOCIAL HISTORY:

EXAMINATION:

Appearance:

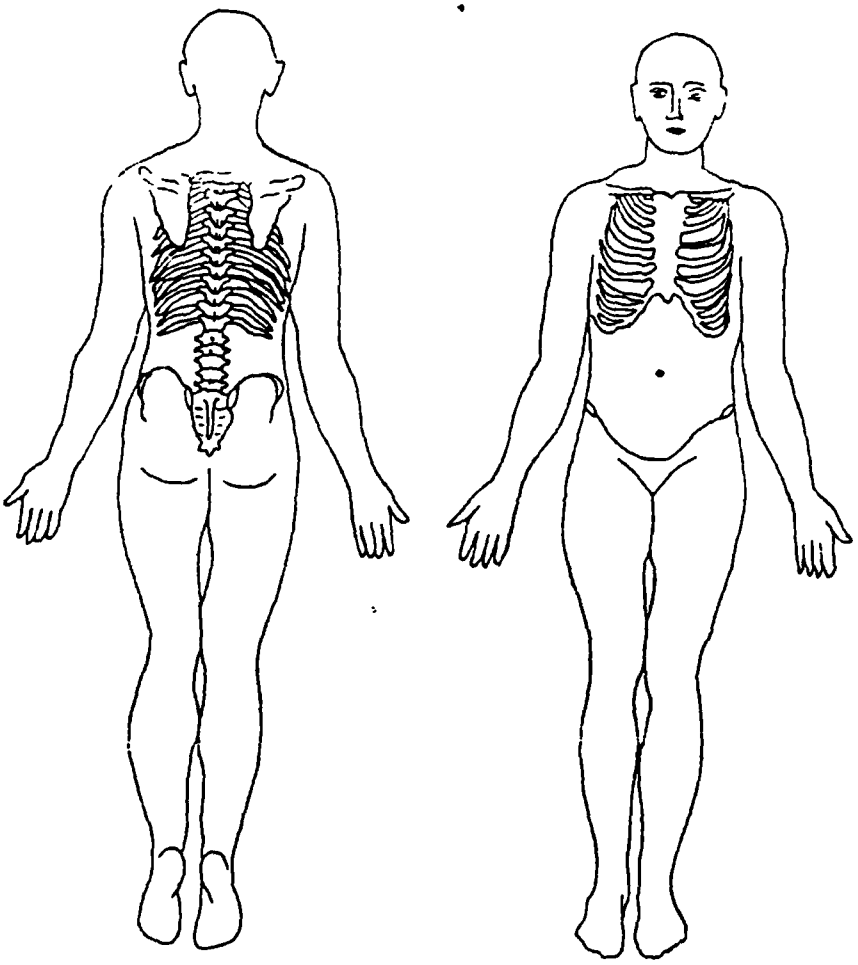
Mouth:

Pressure Areas:

Anaemia	
Cyanosis	
Oedema	
Cachexia	

PROBLEMS:

ACTIONS:



NAME: TEAM NO:

PRESENT CONDITION:
DATE:

WEIGHT
APPETITE
TASTE CHANGE

NAUSEA
VOMITING
DYSPHAGIA

BOWELS
MICTURITION
DISCHARGE

DYSPNOEA
COUGH
SPUTUM

WEAKNESS
HEADACHE
INSOMNIA

BLEEDING
BEDSORES
OEDEMA

MOBILITY

OTHER

NAME: TEAM NO:

RECORD OF PATIENT'S INSIGHT AND UNDERSTANDING OF ILLNESS (IN PATIENT'S OWN WORDS IF POSSIBLE).
Please enter any relevant comments from other members of the family (identify the person concerned!)

DATE:

2 [1] [2-3] [4-7]

FOLLOW-UP

1. DISCHARGED/PENDING

DATE

Days from referral to discharge [8-11]

Reason [15]
1. Left area
2. Non Bloomsbury Resident/ Ward care only
3. Long term Hospice/Nursing Home care
4. Refused
5. Disease regressed/Too early
6. Inappropriate because....
7. Other

2. DIED [8]

DATE

Days from referral to death [12-14]

Place of death [16]
1. Home
2. Hospital
3. Hospice

BEREAVEMENT FOLLOW-UP

1. NO

REASON [18]
1. No relatives
2. Relatives live out of area
3. Not enough contact
4. Refused
5. No need because.....
6. Other

2. YES [17]

NUMBER OF PEOPLE. [9]

NAMES

Relations to patient
1. Wife [20]
2. Husband [21]
3. Daughter [22]
4. Son [23]
5. Sister [24]
6. Brother [25]
7. Friend [26]
8. Other [27]

DATE PLANNED
Number of weeks after loss [28-29]

MODE OF CONTACT [30]
1. Visit
2. Letter
3. Card
4. Telephone
5. Other

BY [31]
1. Sister
2. Doctor
3. Social Worker

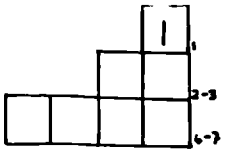
NOTES / ADDITIONAL INFORMATION [32-33]

1-3
4-7

SHEET NO 1

	DATE													
	WEEK	0	1	2	3	4	5	6	7	8	9	10	11	12
8	Pain control													
	Other symptom control													
	Patient anxiety													
	Family anxiety													
	Patient insight													
	Family insight													
	Predictability													
	Planning													
	Practical													
	Financial													
	Wasted time													
	Spiritual													
	Comm between patient & family													
	Comm between professionals													
	Comm profs to patient & family													
	Professional anxiety													
	Advising profs													
25-26	TOTAL													
	CONTACT WITH TEAM													
28-29	Key team worker													
	DAYS IN *Home*													
	Hospital													
	Hospice													
33-34	OTHER MAIN SYMPTOM													
35-37	KARNOFSKY													
	QL Mobility													
	QL Daily living													
	QL Health													
	QL Support													
	QL Outlook													
43-44	QL TOTAL													

Team B



NAME SEX M/F

AGE

POST CODE

Status 1. Married 2. Widowed 3. Divorced/Separated
4. Single 5. Other

Nationality 1. British 2. Irish 3. Greek 4. Italian
5. Asian 6. W. Indian 7. African 8. Other

Religion 1. C/E 2. R. Catholic 3. Greek Orthodox
4. Jewish 5. Other Religion
6. Atheist 7. Agnostic

Living alone
or living with 1 2 3 4 5 Others

NEAREST CARER

1. Wife 2. Husband 3. Daughter 4. Son 5. Sister
6. Brother 7. Friend 8. Other

Carer's Work 1. Part-time 2. Full-time 3. No job 4. Retired

Carer's Karnofsky

G.P.
Address:

Hospital:

DIAGNOSIS

Date first diagnosed

Metastatis 1. 2.

Other diagnoses causing symptoms

1.

2.

DISEASE SITE MOST ACTIVE

1. Primary site 2. Metastatis 3. Other diagnosis

Referred by

1. GP 2. Radiotherapist 3. Oncologist 4. Surgeon
5. Physician 6. Other

Name of Referrer

Date of Referral

Time diagnosis to referral

(1) 0 - 1 mth (2) 1 - 3 mths (3) 3 - 6 mths (4) 6mths - 1 year
(5) 1 - 2 years (6) 2 - 3 years (7) 3 - 5 years (8) 5+ years

REASONS FOR REFERRAL 1.

2.

SOCIAL CIRCUMSTANCES

ACCOMMODATION:
1. Owner occupied 2. Private rented 3. Council 4. Hostel 5. Other

ACCESS:
1. Ground Floor 2. By lift 3. By stairs

2 [ ][ ][ ][ ] 2-3 4-7

FOLLOW-UP

1. DISCHARGED/PENDING [ ] 8

DATE

Days from referral to discharge [ ][ ][ ] 9-11

Reason [ ] 15
1. Left area
2. Not resident in home care area/ Ward care only
3. Long term Hospice/Nursing Home care
4. Refused
5. Disease regressed/Too early
6. Inappropriate because....
7. Other

2. DIED

DATE

Days from referral to death [ ][ ][ ] 12-14

Place of death [ ] 16
1. Home
2. Hospital
3. Hospice

BEREAVEMENT FOLLOW-UP

1 NO [ ] 17

REASON [ ] 18
1. No relatives
2. Relatives live out of area
3. Not enough contact
4. Refused
5. No need because.....
6. Other

2 YES [ ] 17

NUMBER OF PEOPLE. [ ] 19

NAMES

Relations to patient
1. Wife [ ] 20
2. Husband [ ] 21
3. Daughter [ ] 22
4. Son [ ] 23
5. Sister [ ] 24
6. Brother [ ] 25
7. Friend [ ] 26
8. Other [ ] 27

DATE PLANNED
Number of weeks after loss [ ][ ] 28-29

MODE OF CONTACT [ ] 30
1. Visit
2. Letter
3. Card
4. Telephone
5. Other

BY [ ] 31
1. Sister
2. Doctor
3. Social Worker

NOTES / ADDITIONAL INFORMATION

[ ][ ] 32-33

	3				1-3									
					4-7									
	DATE													
	WEEK	0	1	2	3	4	5	6	7	8	9	10	11	12
8	Pain control													
	Other symptom control													
	Patient anxiety													
	Family anxiety													
	Patient insight													
	Family insight													
	Predictability													
	Planning													
	Practical													
	Financial													
	Wasted time													
	Spiritual													
	Comm. between patient & family													
	Comm. between professionals.													
	Comm. profs to patient & family													
	Professional anxiety													
	Advising profs.													
1-26	TOTAL													
	CONTACT WITH TEAM													
27-29	Key team worker													
	DAYS IN Home													
	Hospital													
	Hospice													
	OTHER MAIN SYMPTOM													
33-34														
35-37	KARNOFSKY													
	38-43 (9)													
45	Team anxiety													
	COMMENTS													

Team C

Date of first contact .....

Request for help/Referral Form

.p Requested By .....Designation .....

Behalf Of .....Location Hospital.....

Community.....

D.A.U.....

O.P.D.....

<u>e Contact Was Made</u> Initiated by Requestor.....

Initiated by Self.....

ASONS FOR REFERRAL 1.

2.

tient's Name.....Age.....Telephone Number.....

dress.....

atus 1. Married 2. Widowed 3. Divorced/Separated 4. Single 5. Other

tionality 1. British 2. Irish 3. Greek 4. Italian 5. Asian
6. W. Indian 7. African 8. Other

ligion 1. C/E 2. R.Catholic 3. Greek Orthodox 4. Jewish 5. Other
6. Athiest 7. Agnostic

VING ALONE
. LIVING WITH 1 2 3 4 >5 OTHERS

:y Person/Next of Kin.....Telephone Number.....

<u>LATION</u> 1. Wife 2. Husband 3. Daughter 4. Son 5. Sister 6. Brother
7. Friend 8. Other

<u>)RK</u> 1. Part/ 2. Full-time 3. No Job/ 4. Retired Carer's Karnofsky |__|__|__|

P.....Telephone Number.....

ıse..... District Nurse.....

:her.....

:AGNOSIS.....

DATE FIRST DIAGNOSED.....

<u>:TASTASIS</u> 1. 2.

<u>:HER DIAGNOSIS CAUSING SYMPTOMS</u> 1. 2.

<u>:SEASE SITE MOST ACTIVE</u> 1. PRIMARY SITE 2. METASTASIS 3. OTHER DIAGNOSIS

ıme diagnosis to referral (1) 0-1 mth (2) 1-3 mths (3) 3-6 mths (4) 6 mths-1 year
(5) 1-2 yrs (6) 2-3 yrs (7) 3-5 yrs (8) 5+ yrs

:COMMODATION: 1. Owner occupied 2. Private rented 3. Council 4. Hostel
5. Other

:CESS: 1. Ground floor 2. By lift 3. By stairs

P. Weeks: from |__|__| (53-54) to |__|__| (55-56)

SUMMARY OF WORK

With whom did you work? Patient/Family/Requestor/Other Staff

Other Staff: Cons./Jnr Doctor/Sister/Staff Nurse/SEN/Student Nurse/S.W./
G.P./D.N./Health Visitor/Home Help/Agency Nurse/Priest/Other

	In Hospital	At Home
How many times did you see the patient alone?	|____|	|____|
How many times did you see the patient with staff?	|____|	|____|
How many times was contact made by telephone?	|____|	

	In Hospital	At Home
How many times did staff contact us?	|____|	|____|
How many times did you contact the staff?	|____|	|____|

DISCHARGED/PENDING DATE_____

Reason 1. Left area 2. Non-Resident/Ward care only
3. Long term Hospice/Nursing Home 4. Refused 5. Disease regressed/Too early
6. Inappropriate because..... 7. Other

DIED From Cancer/Other Date_____

SUDDEN DEATH Yes/No

Where did the patient die? 1. Home 2. Hospital 3. Hospice

BEREAVEMENT FOLLOW-UP

1. NO

REASON

1. No relatives
2. Relatives live out of area
3. Not enough contact
4. Refused
5. No need because.....
6. Other

2. YES NUMBER OF PEOPLE
NAMES

Relations to patient
1. Wife |___|
2. Husband |___|
3. Daughter |___|
4. Son |___|
5. Sister |___|
6. Brother |___|
7. Friend |___|
8. Other |___|

DATE PLANNED
Number of weeks after loss |___|___|

MODE OF CONTACT:
1. Visit
2. Letter
3. Card
4. Telephone
5. Other

BY.
1. Sister
2. Doctor
3. Social Worker

DATE						
WEEK NUMBER	0	1	2	3	4	5
GOALS						
SYMPTOMS: -						
1. PAIN						
2. OTHER						
ANXIETY:-						
1. PATIENT						
2. FAMILY						
INSIGHT:-						
1. PATIENT						
2. FAMILY						
PREDICTABILITY						
PLANNING						
PRACTICAL						
FINANCIAL						
WASTED TIME						
SPIRITUAL						
COMMUNICATION:-						
1. PATIENT TO FAMILY						
2. BETWEEN PROFESSIONALS						
3. PROFESSIONALS TO PATIENT AND FAMILY						
PROFESSIONAL ANXIETY						
ADVISING PROFESSIONALS						
OTHER MAIN SYMPTOM						
CONTACT						
KEYWORKER(S)						
DAYS IN:-						
- HOME						
- HOSPITAL						
- HOSPICE						
KARNOFSKY						
COMMENTS -plus (Carer's Karnofsky if changing)						

Team D

1	0	4	1-3
			4-7
			8

9-10

NAME
DATE OF BIRTH
ADDRESS

SEX M / F
AGE
ACCESS ROUTE

Area: 1. Hammersmith 2. Fulham 3. Chiswick 4. White City 5. Earls Court
6. Middlesex 7. Out of Area

PHONE NUMBER

11

Status 1. Married 2. Widowed 3. Divorced / Separated 4. Single 5. Other
Nationality 1. British 2. Irish 3. Greek 4. Italian 5. Asian
6. W. Indian 7. African 8. Other
Religion 1. C / E 2. R. Catholic 3. Greek Orthodox 4. Jewish 5. Other Religion
6. Atheist 7. Agnostic
LIVING ALONE
OR LIVING WITH 1 2 3 4 >5_ OTHERS

12
13
14
15

NEAREST CARER

16

RELATION 1. Wife 2. Husband 3. Daughter 4. Son 5. Sister 6. Brother 7. Friend 8. Other
ADDRESS

WORK 1. Part / 2. Full-time
3. No Job / 4. Retired

17

Carer's Karnofsky

18-20

PHONE NUMBER
KEY RELATIVES OR OTHER FRIENDS

G.P.
ADDRESS

PHONE NO.

DISTRICT NURSES

HY / GY

SOCIAL WORKER

SOCIAL SERVICES / OTHER AGENCIES

HOSPITAL NUMBER

21-23

HOSPITAL
WARD

24-25

CONSULTANTS

OTHER HOSPITAL STAFF

HOSPITAL SOCIAL WORKER

DIAGNOSIS [ ] 26

DATE FIRST DIAGNOSED [ ][ ][ ][ ] 27-30

METASTASIS 1. [ ] 31 2. [ ] 32

OTHER DIAGNOSES CAUSING SYMPTOMS

1. [ ][ ] 33-34

2. [ ][ ] 35-36

DISEASE SITE MOST ACTIVE 1. PRIMARY SITE [ ] 37
2. METASTASIS
3. OTHER DIAGNOSIS

REFERRED BY 1. GP 2. Radiotherapist 3. Oncologist 4. Surgeon 5. Physician 6. Other [ ] 38

NAME [ ][ ][ ] 39-41

DATE OF REFERRAL [ ][ ][ ][ ] 42-45

Time diagnosis to referral: 1. 0-1 mth 2. 1-3 mths 3. 3-6 mths 4. 6 mths - 1 year 5. 1-2 yrs
6. 2-3 yrs 7. 3-5 yrs 8. 5+ yrs [ ] 46

DATE FIRST SEEN

REASONS FOR REFERRAL 1. [ ][ ] 47-48

2. [ ][ ] 49-50

Other Main Problems at Referral:

Drugs at Referal

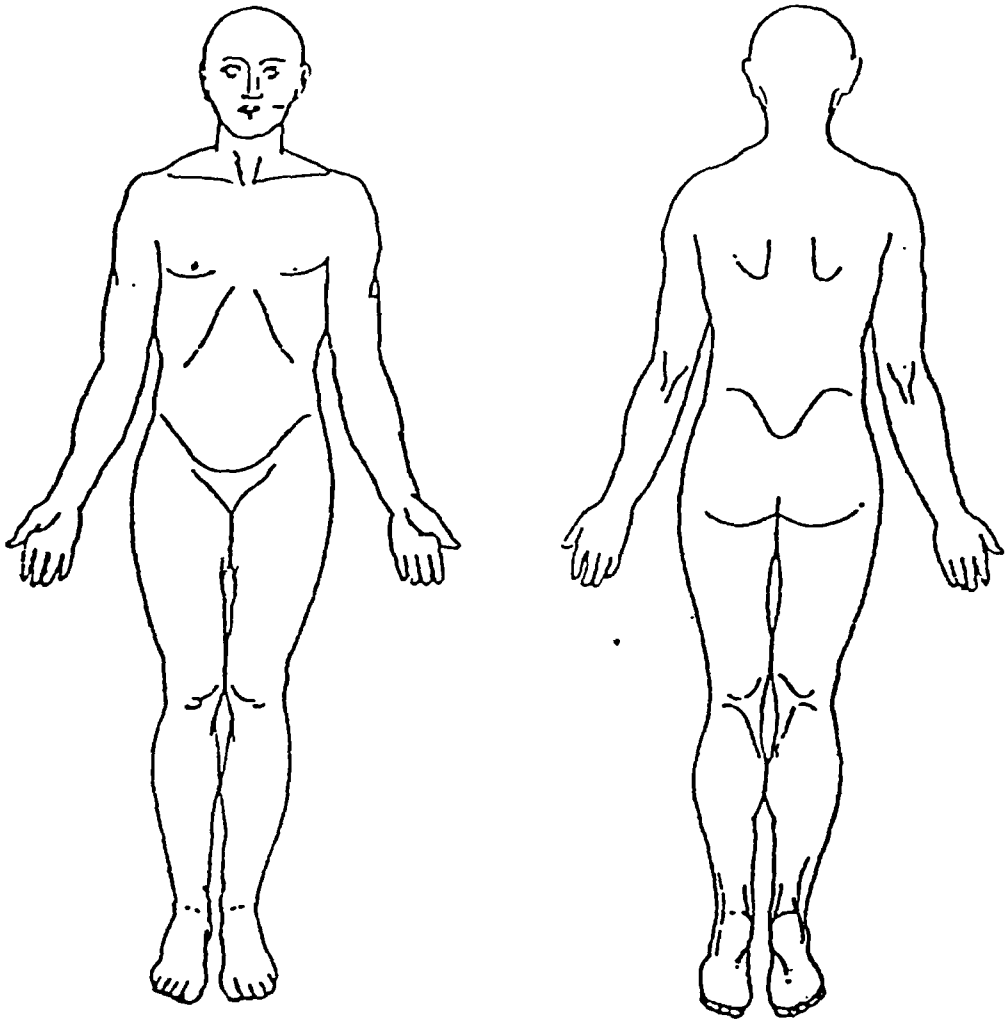
SOCIAL CIRCUMATANCES:

ACCOMODATION: 1. Owner occupied 2. Private rented 3. Council 4. Hostel 5. Other [ ] 51

ACCESS: 1. Ground floor 2. By lift 3. By stairs [ ] 52

NOTES / OTHER RELEVANT INFORMATION

Prognosis estimate: from [ ][ ] to [ ][ ] weeks 53-54 55-56



	INTENSITY	DURATION	NATURE & COMMENTS
	None Mild Moderate Severe Overwhelming	weeks / months	e.g. Intermittent or Constant Sharp / Dull / Colic
PAIN 1			
PAIN 2			
OTHER PAINS			

12 | 04

FOLLOW-UP

1. DISCHARGED/PENDING

DATE

Days from referral to discharge ☐☐☐

Reason
1. Left area
2. Non Resident in Home care area / Ward care only
3. Long term Hospice/Nursing Home care
4. Refused
5. Disease regressed/Too early
6. Inappropriate because....
7. Other

2. DIED

DATE

Days from referral to death ☐☐☐

Place of death
1. Home
2. Hospital
3. Hospice

BEREAVEMENT FOLLOW-UP

1. NO

REASON
1. No relatives
2. Relatives live out of area
3. Not enough contact
4. Refused
5. No need because.....
6. Other

2. YES

NUMBER OF PEOPLE. ☐

NAMES .

Relations to patient
1. Wife
2. Husband
3. Daughter
4. Son
5. Sister
6. Brother
7. Friend
8. Other

DATE PLANNED
Number of weeks after loss ☐☐

MODE OF CONTACT
1. Visit
2. Letter
3. Card
4. Telephone
5. Other

BY
1. Nurse
2. Doctor
3. Social Worker

NOTES / ADDITIONAL INFORMATION

3	0	4	1-3
			4-7

		0	1	2	3	4	5	6	7	8	9	10	11	12
	DATE													
	WEEK													
8	Pain control													
	Other Symptom control													
	Patient anxiety													
	Family anxiety													
	Patient insight													
	Family insight													
	Predictability													
	Planning													
	Practical													
	Financial													
	Wasted time													
	Spiritual													
	Comm. between patient & family													
	Comm. between professionals.													
	Comm. profs to patient & family													
	Professional anxiety													
	Advising profs.													
25-26	TOTAL													
	CONTACT WITH TEAM													
28-29	Key team worker													
	DAYS IN Home													
	Hospital													
	Hospice													
33-34	OTHER MAIN SYMPTOM													
35-37	KARNOFSKY													
	COMMENTS													
38-45	(9)													
46-47														

Team E

Initial Assessment
Sheet 1

1 | 0 5 | 1 | 2-3 | 4-7

Hospital No.
Patient No.

Date:
Place:

Name:
Address:

M / F
Age:

D. of B.
O/c of Pt:
O/c of H/H

8 | 9-10

Tel :

Area: 1. Bickley 2. Biggin Hill 3. Bromley 4. Orpington 5. Chislehurst
6. Petts Wood 7. Farnborough 8. St. Paul's Cray 9. St. Mary's Cray
10. Other

Map Ref:

11

Status 1. Married 2. Widowed 3. Divorced/Sep 4. Single 5. Other 12

Nationality 1. British 2. Irish 3. Greek 4. Italian 5. Asian
6. W. Indian 7. African 8. Other 13

Religion 1. C/E 2. R. Catholic 3. Greek Orthodox 4. Jewish
5. Other Religion 6. Atheist 7. Agnostic 14

Living alone _____ or living with 1 2 3 4 5+ Others 15

Nearest Carer:
Relation 1. Wife 2. Husband 3. Daughter 4. Son 5. Sister 6. Brother
7. Friend 8. Other 16

Address:

Carer's Work 1. Part/ 2. Full-time
2. No Job 4. Retired 17

Carer's Karnofsky 18-20

Tel:

G.P.

Address:

Hospital

Consultants:

21-23 | 24-26

Tel:

Diagnosis 27

Date first diagnosed: 28-30

Metastasis: 1. 31
2. 32

Other diagnoses causing symptoms:
1. 33-34
2. 35-36

Disease site most active: 1. Primary site 2. Metastasis 3. Other diagnosis 37

Referred by: 1. G.P. 2. Radiotherapist 3. Oncologist 4. Surgeon 5. Physician 6. Other ☐ 37

NAME: ☐☐☐ 38-40

Date of referral ☐☐☐☐ 41-44

Time diagnosis to referral

(1) 0-1 mth (2) 1-3 mths (3) 3-6 mths (4) 6 mths - 1 year
(5) 1-2 year (6) 2-3 year (7) 3-5 years (8) 5+ years ☐ 45

Reasons for Referral: 1. ☐☐ 46-47

2. ☐☐ 48-49

Present Condition

Appetite	Nausea	Vomiting	Dysphagia	Weight
Bowels	Mict.	Incont.	Discharges	Bleeding
Sleep	Cough	Dyspnoea	Bedsores	Oedema
Weakness	Headaches	Anxiety	Confusion	Depression
Pain	Sore Mouth		Vision	Hearing

H.P.C.

P.M.H.

Cigarettes Alcohol

Social circumstances:

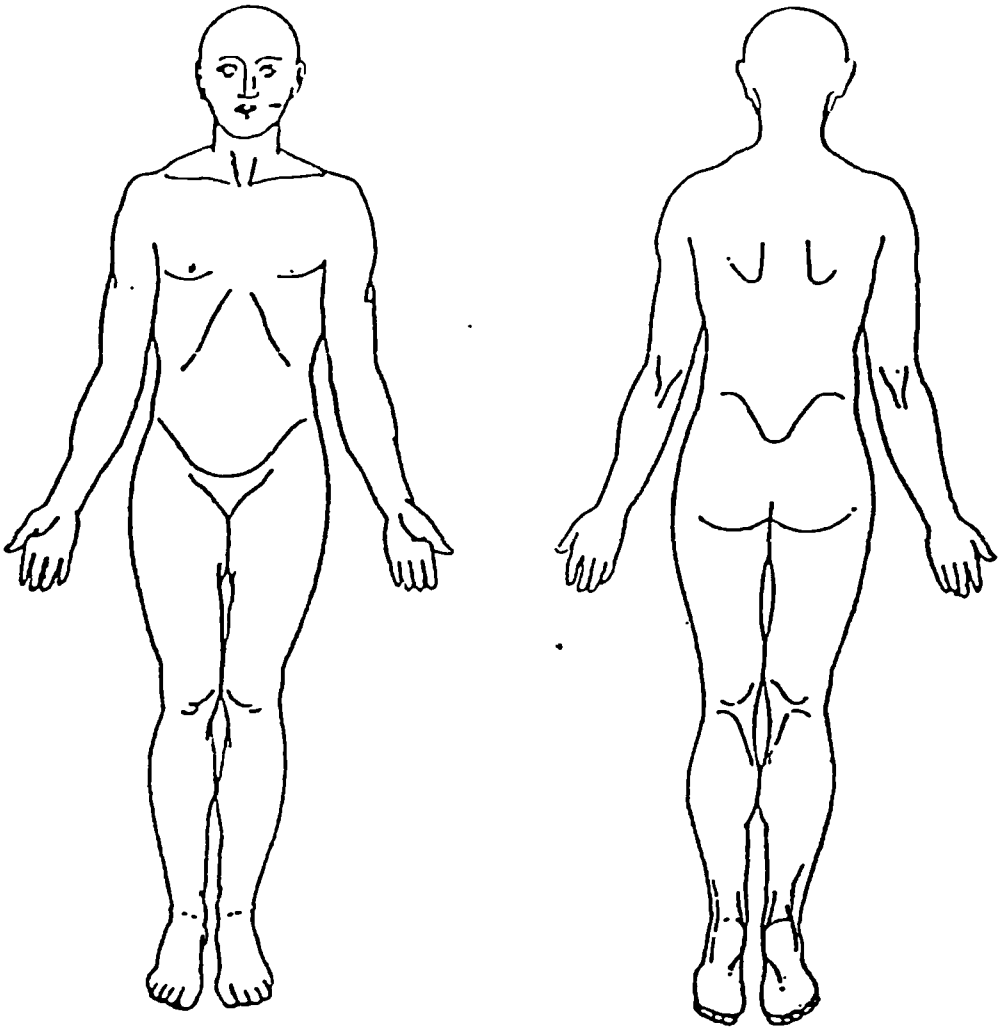
Accomodation

1. Owner occupied 2. Private rented 3. Council 4. Hostel 5. Other ☐ 51

Access

1. Ground Floor 2. By Lift 3. By Stairs ☐ 52

Prognosis estimate: weeks from ☐☐ to ☐☐ 53-54 55-56



	INTENSITY	DURATION	NATURE & COMMENTS
	None Mild Moderate Severe Overwhelming	weeks / months	e.g. Intermittent or Constant Sharp / Dull / Colic
PAIN 1			
PAIN 2			
OTHER PAINS			

Observation

Mobility

Insight

(a) Patient

(b) Family

Auxiliary services

G.P.	O.T.
D/N	SBH Volunteer
PHYSIO	M.O.W.
S.W.	H.H.
H.V.	OTHER

SOCIAL RECORD	GRANTS – BENEFITS	Existing	Applied For
Admission	Supplementary Benefit		
Diagnosis	Mobility		
	Attendance		
	Invalid Care		
Change of diagnosis	NSCR		

DATE	REPORT AND RECORD (Each entry must be signed)
	Space for family tree

[2] [0 5]

FOLLOW-UP

1. DISCHARGED/PENDING

DATE

Days from referral to discharge [ ][ ][ ]

Reason
1. Left area
2. Non Resident / Ward care only
3. Long term Hospice/Nursing Home care
4. Refused
5. Disease regressed/Too early
6. Inappropriate because....
7. Other

2. DIED [ ]

DATE

Days from referral to death [ ][ ][ ]

Place of death
1. Home
2. HA Hospital
2b. Other Hospital
3. Hospice

BEREAVEMENT FOLLOW-UP

1. NO

REASON
1. No relatives
2. Relatives live out of area
3. Not enough contact
4. Refused
5. No need because.....
6. Other

2. YES [ ]

NUMBER OF PEOPLE. [ ]

NAMES

Relations to patient
1. Wife [ ]
2. Husband [ ]
3. Daughter [ ]
4. Son [ ]
5. Sister [ ]
6. Brother [ ]
7. Friend [ ]
8. Other [ ]

DATE PLANNED
Number of weeks after loss [ ][ ]

MODE OF CONTACT
1. Visit
2. Letter
3. Card
4. Telephone
5. Other [ ]

BY
1. Nurse
2. Doctor
3. Social Worker
4. Voluntary Bereavement Carer
5. C [ ]

Contact with Patient

	Visits (+OPD)	Phone
Day		
Night		
Total		

Adjuvant Therapy [ ][ ]

R/T
Chemotherapy
NB
Flotron
SD

3	0	5	1-3
			4-7

		WEEK	0	1	2	3	4	5	6	7	8	9	10	11	12
		DATE													
8		Pain control													
		Other Symptom control													
		Patient anxiety													
		Family anxiety													
		Patient insight													
		Family insight													
		Predictability													
		Planning													
		Practical													
		Financial													
		Wasted time													
		Spiritual													
		Comm. between patient & family													
		Comm. between professionals.													
		Comm. profs to patient & family													
		Professional anxiety													
		Advising profs.													
25-26		TOTAL													
		CONTACT WITH TEAM													
28-29		Key team worker													
		DAYS IN Home													
		Hospital													
		Hospice													
33-34		OTHER MAIN SYMPTOM													
35-37		KARNOFSKY													
		COMMENTS													
38-45		(9)													
46-47															